Respect and shared decision making in the clinical encounter, A Video-Reflexive Ethnography

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Dedication

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Abstract

Background: Shared decision making (SDM) is a key component for improving the quality of healthcare delivery in the Affordable Care Act (2010). In practice, there is less implementation of SDM than was expected when the ACA was passed. Respecting patient's preferences and values is integral to the definition of patient centered care (PCC) and as SDM is often described as one way of operationalizing PCC it seems intuitive that respect is important for SDM. The aim of this study was to describe what respect means to both patients and clinicians and to determine whether respect is related to shared decision making in primary care clinical encounters.

Methods: A Video-Reflexive Ethnography (VRE) with 40 hours of video recordings from 15 primary care clinical encounters and 27 video-reflexivity sessions. Clinicians, patients and caregivers were invited to share their perspectives on respect and decision making in individual reflexivity sessions. Data collection and analysis were iterative. Analysis began during the focused ethnography. It continued with the researcher editing video-recordings of the clinical encounter into shorter 2-4 minute video-clips that were shared with participants in reflexivity sessions. The 27 one-hour video-reflexivity sessions were also video-recorded and transcribed for further data. During the reflexivity sessions, there was further analysis with participants as collaborators in the research. Finally, a grounded theory analysis of the transcripts of the video-recorded data was conducted.

Results: This study extends current descriptions of respect to include respect for both 'patients and clinicians as persons' in a broader context than the clinical encounter. Another unexpected finding is the affective and emotional aspect of respect conveyed through 'feeling comfortable,' described as feeling 'at ease' and 'not threatened' in the encounter. Respect is described as of value to both participants in terms of valuing individuality (patients and clinicians as persons in a broader social context), valuing agency (patients' ability to influence their health and their treatment plans) and valuing feeling comfortable. A surprising result was how respect is related to SDM. Respect is relevant and valued in all types of decision making in primary care clinical encounters (clinician-led, patient-led and shared). This resulted in a revised understanding of SDM from a point in time exercise where a decision is made by one or both participants to an acknowledgment that in primary care it is a decision-making process, carried out over time. Regardless of who makes the decision, participants described attributes of respect that enabled them to accept the process and the decision. Throughout the clinical encounter, clinicians highlighted institutional factors that influenced the extent to which respect was evident. Both patients and clinicians described respect as being co-created by them interacting in the encounter in ways that involved additional work and effort.

Conclusion: Respect is valued by both patients and clinicians, but it is not always easy to practice. Training and re-structuring the institutional constraints that clinicians face may facilitate respectful encounters. Respect may influence patients wanting to see their clinician again improving continuity of care; may encourage both clinicians and patients to open up in ways that strengthen the relationship; and may lead to partnership in treatment planning affecting adherence.

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Introduction
1.1 Background

Recent healthcare reform in the United States has expanded insurance coverage for many previously uninsured individuals (Chang & Davis, 2013). In theory, coverage will facilitate access to healthcare and improved health outcomes. However, access to care is not enough – quality also matters. Low quality healthcare is associated with lack of continuity of care, non-adherence, increases in hospital and emergency visits, and interestingly, a subsequent distrust in primary healthcare providers (Kangovi et al., 2013). On the contrary, systems that promote quality primary care have lower per capita costs and better health outcomes (Starfield, Shi, & Macinko, 2005).

Patient centered care (PCC) defined as "providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions" was included as one of six aims that the Institute of Medicine recommended to address healthcare quality in the United States (IOM, 2001). The goal of the patient and the clinician in a clinical encounter is to come to a mutually agreeable decision about managing the patient's condition. The treatment decision may involve a range of options, including surgery, medical therapy, continuing the present

treatment or reviewing the decision at a later date. When decisions are shared, there is also a degree of 'sharing power and responsibility' (Mead & Bower, 2000). Shared decision making (SDM) is described as a process whereby clinicians share the best available evidence about treatment options with patients, including the risks and benefits of each option, and patients are able to share their values and preferences for the treatment options under consideration (Elwyn et. al, 2012). Together, clinicians and patients reach a decision about the right treatment for that individual patient at that time. The challenge remains to implement shared decision making so that it can be a 'critical component of quality and safety' (Barry & Edgman-Levitan, 2012). Oshima Lee and Emmanuel believe that SDM could lead to 'improved quality of care and savings' if it were implemented along with other provisions of the Affordable Care Act (Oshima Lee & Emanuel, 2013).

1.2 Purpose of the Study

National health policy legislation, (ACA 2010), prominently features the concept of shared decision making (SDM) as a means of improving the quality of health care delivery. Yet, there are few guidelines, beyond certifying decision aids, on how SDM should be implemented in practice. SDM includes sharing medical evidence and respecting patients' values and preferences (Elwyn et al., 2012). Intuitively, respect is

important for SDM to occur. I argue that the extent to which SDM is evident in a clinical encounter is influenced by the degree to which respect is present. While there are other important factors in the clinical encounter, many of these have already been studied in the literature such as sharing, empowerment, communication, information and trust. There is however, a dearth of literature on the role of respect. Mary Catherine Beach defines respect within healthcare as "a recognition of the unconditional value of patients as persons" (Beach et al., 2007). Beach and her colleagues at Johns Hopkins are often cited when referring to research on respect, yet these researchers have not attempted to clarify what respect means to patients and clinicians. Instead, they rely on an intuitive understanding of respect and have gathered data through (single item) survey instruments. It is this gap in the literature about the conceptual meaning of respect and how the concept of respect relates to SDM that this study aims to fill.

To develop an understanding of 'respect' that is grounded in the experience of those participating in clinical encounters, this study gives voice to clinicians and patients. Descriptions of the characteristics of respect and what respect means to participants in the context of their clinical encounters is brought to the fore with Video-Reflexive Ethnography, a qualitative methodology that uses video to record in-situ care and to show edited video clips of that care back to patients and clinicians in reflexivity sessions which are also video-recorded and analyzed. A greater understanding of what respect means to

those who are directly participating in primary care clinical encounters may facilitate further implementation of SDM in practice, as envisaged by the Affordable Care Act (2010).

1.3 Research Objectives

A conceptual model describing the study is outlined in Figure 1. The clinical encounter involves a primary care clinician and a patient with a chronic condition who is seeking treatment for a current condition or to prevent future illness. The goal is often to arrive at a treatment decision. In reaching a decision, the clinical encounter may include various factors such as informed decision making where evidence based medicine and patients' goals and values are shared in a partnership which may be considered shared decision making. Respect perceived through clinician behaviors, communication and the physical environment may also influence the treatment decision and how it is reached. Patients' perceptions of the extent to which respect is present in the encounter is the focus of question one (Q1) and clinicians' descriptions of respect in the encounter is the focus of question two (Q2). How respect and shared decision making relate to each other in the clinical encounter is what question three (Q3) aims to answer. Respect and SDM have been described in the existing literature as being related to patient outcomes such as satisfaction, adherence and the willingness to recommend a hospital and seek care from a

particular clinician. In addition, SDM has been justified on ethical grounds as well as outcomes such as increased knowledge and in some cases cost savings.

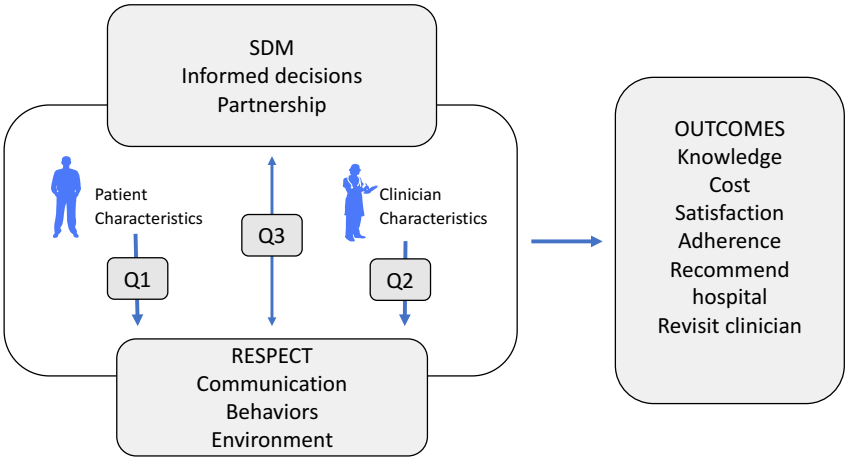

Figure 1: Conceptual model of the study

The focus of the first part of the study is a qualitative analysis of what 'respect' means to both patients and clinicians, and the second part of the study is a qualitative analysis of how respect relates to shared decision making. The first research question is: **How do patients describe 'respect' in the clinical encounter?** Fifteen primary care internal medicine clinicians were recruited purposefully from those who had previously used shared decision aids and conveniently from a sample of clinicians who work in the

Primary Care Internal Medicine Practice at a large Midwestern academic health system. Fifteen adult patients with chronic conditions, who had appointments with the selected primary care clinicians, were conveniently sampled for inclusion in the study. While there is benefit in studying multiple patients with a single provider to determine whether the clinician and patient characteristics influence respect, this was beyond the scope of the current study. Thirteen patients and four caregivers participated in reflexivity sessions.

I obtained consent to sit in on fifteen clinical encounters and to video-record the visits. Video-Reflexive Ethnography (VRE), a collaborative qualitative methodology described as 'the practice of filming professionals at work and sharing with them the resulting footage with the aim of engendering discussion about their work' (Iedema, Mesman, & Carroll, 2013) was applied. VRE has been utilized in previous studies to improve the quality of care in healthcare settings (Forsyth 2009; Forsyth, Carroll & Reitano, 2009; Iedema, 2009). VRE was originally used to study clinical teams and recently has been extended to study patients as well (Collier & Wyer, 2016). This study extends the methodological approach of VRE studies with patients. Here I video-recorded participants in the clinical encounter, and reviewed the video-graphic data with them (Question 1 relies on data from the review with patients). Capturing video-footage and reviewing it with participants deepens our knowledge of how they experienced the

complexity of the visit, and has the potential to stimulate new interpretations of events, behaviors or processes for patients. Additionally, VRE with patients provides the opportunity for patients to be actively engaged in a research context to which they do not usually have access.

After video-recording and transcribing the reflexivity sessions for additional data to answer research question 1, grounded theory methods, described as "systematic yet flexible guidelines for collecting and analyzing qualitative data to construct theories from the data themselves" (Charmaz, 2014) was used to classify themes that emerged, to develop a description of respect in the clinical encounter. Grounded theory was used because its strength lies in the simultaneous collection and analysis of data. In the constructivist school of grounded theory, the interaction between researcher and participants is encouraged, especially in the co-production and interpretation of the data (Charmaz, 2014). As such, the researcher may modify initial questions based on analysis of the first observation and can modify interview guides to include new concepts generated from the data. Data collection and analysis is iterative, such that data originally gathered informs the interview guides of further data collection. All data gathered, regardless of the stage at which it is gathered is relevant. In this way, grounded theory is forgiving of the inexperienced researcher who will gain experience and confidence over time as the data collection and interviews continue (Charmaz, 1990).

The second research question, **how do clinicians describe 'respect' in the clinical encounter?** followed the same methodology as the first question with patients. The same video-taped encounters (N=15) that provided data to answer the first research question were used to answer the second, although for the second question 14 video-reflexivity sessions were conducted with individual clinicians. All video-reflexivity sessions were video-recorded and were transcribed. Grounded theory was used to analyze the transcribed video-graphic data. After coding the transcribed reflexivity sessions of patients and clinicians separately in research questions 1 and 2, the video-recorded data was analyzed to develop themes on how patients and clinicians perceive respect in the clinical encounter.

The description of respect developed in the initial phase of this research study was used to address the third research question, **how do patients and clinicians relate respect to shared decision making in the encounter?** Of the 15 video-recorded clinical encounters, the final 7 clinical encounters were analyzed to focus specifically on decision making in the encounter. Saturation was reached after 6 clinicians and 5 patients were invited to review edited clips of decision making instances in their encounters, during 11 separate one-hour video-reflexivity sessions. Again, the reflexivity sessions were video-recorded and transcribed. Here analysis focused on how decisions were made and who

participated as well as the way in which participants described how decision making is related to respect.

While VRE has traditionally been employed to study processes in healthcare practices with team-based semi-structured reflexivity sessions (Carroll, Iedema & Kerridge, 2008; Carroll & Mesman, 2011; Hor, 2014; Iedema, 2009; Iedema et al., 2013); this study has used VRE in a relatively new way by recruiting both patients and clinicians. Reflexivity sessions were conducted individually (as opposed to the traditional team based sessions) to mitigate any vulnerability patients with chronic conditions may have reflecting on their clinician's behaviors in their presence.

VRE is a three-phase approach (Collier & Wyer, 2016), Phase 1: establishing trust and engaging in a video-ethnography by interviewing, observing and video-recording front-line practices; Phase 2: edited video-clips are shared with participants in video-reflexivity sessions and Phase 3: research is shared with stakeholders to optimize practice. The findings will be shared with the practice where the research took place. The intention is for the practice to decide how this research can be translated into practice (education, training and practical suggestions to create respectful clinical encounters).

1.4 Significance of the Study

This study analyzes the concept of 'respect' in the clinical encounter and how it is related to shared decision-making (SDM). This study is relevant for policymakers as patient centered care and SDM feature prominently in recent national healthcare policy such as the Patient Protection and Affordable Care Act of 2010. The ACA (Section 936) encourages a standardization and certification of patient decision aids so that patients may incorporate their preferences in decisions regarding their treatment options. However, the ACA does not define patient centered care and how it can be operationalized through SDM. Understanding the role of respect on the shared decision making process may make implementation of SDM more effective, less variable and lead to an improved quality of care for patients. As this study uses grounded theory methodology and specifies the conditions under which respect may be observed, the results are applicable more broadly where other hospital systems identify similar conditions. The emergent theory of respect may form the basis of a larger study and could inform how patients, clinicians, administrators and policymakers think about the clinical encounter and ways of maximizing the healthcare benefits for both clinicians and patients, particularly continuity of care, adherence and an improved healthcare experience.

Chapter Two
Respect and the Clinician-Patient Relationship

The clinician-patient relationship is unique in its intimacy and importance for patients seeking medical advice on the available treatment options for their health conditions or advice about how to prevent illness. This chapter will explore a theoretical frame of respect within social justice and then discuss how respect has been conceptualized over time in various models of the clinician-patient relationship. For many, including health policy advocates, the preferred form of healthcare delivery today is 'patient centered' (IOM, 2001). In deconstructing the term 'patient centered care', I will specifically focus on respect. I will also look at how PCC is operationalized in clinical encounters today through shared decision-making. Thereafter, the discussion returns to a conceptual overview of respect in healthcare. The chapter concludes with a review of the existing literature on studies of respect in healthcare and describes the main policy implications of these studies. The limitations of these studies, in defining and measuring respect, are also highlighted.

2.1 Conceptualizing Respect in a Social Justice frame

The etiology of the word 'respect' can be traced back to the 14th Century and derives from the Latin word *respicere*, meaning to 'look back at' or 'regard' (Webster dictionary 2014). This meaning of respect involves the sentiment of noticing someone a

second time, or in more depth, and is associated with holding someone in high regard. The renowned political philosopher John Rawls claimed that "one of the entitlements that individuals are due by virtue of their humanity is the right to be treated in a way that fosters positive self-regard" (Rawls, 1971). As an inherently moral principle, respect can be viewed as a basic right of persons. The concept of assigning basic rights to all citizens is based on Rawls' "justice as fairness" philosophy; justice should equally and fairly assign rights and duties to all citizens (Rawls, 1971). Framing respect in healthcare within Rawls' social justice theory suggests that all patients should be treated respectfully in an equal and fair manner.

Respect is further categorized as a 'primary ethical principle' (Browne, 1993). It is of moral value in the bioethical literature, relating to the autonomy of individuals, following the Kantian philosophy that "individuals have inherent intrinsic value" (Browne, 1993). However, this narrow definition of respect for persons based on autonomy has been challenged elsewhere in the literature to include those persons, who are not autonomous, those who may not be able to make rational decisions, but should also be respected (Beach et al., 2006).

It is argued that respect is a moral obligation as a well as a right based on one's humanity (Denier, 2005; Morris, 1997). Respect is accorded when assigning worth or value to individuals, (Clucas & St Claire, 2010) and both respect and worth are seen as

components of human behavior (Hendrick, 2006). Respect is also viewed as "akin to positive regard, a belief that enables one to value other people, institutions and traditions" (Schwalb & Schwalb, 2006). As such, the authors suggest that respect is "essential in civil society and crucial to positive human relations" (Schwalb & Schwalb, 2006).

Respect is present in some form, on a continuum from none to full respect, in all our social engagements with others and may vary by person, place and context. Disrespect, which this study does not aim to define, may be considered as the negative end of this continuum. Respect is often assumed to be synonymous with empathy and dignity (Bayne, Neukrug, Hays, & Britton, 2013; Beach et al., 2005; Browne, 1993; Joffe, Manocchia, Weeks, & Cleary, 2003; Manookian, Cheraghi, & Nasrabadi, 2014). Behaviors such as eye contact and communication styles, such as not interrupting, play a role in demonstrating respect for others (Morris, 1997). The specific types of behaviors that reflect respect, however, are person and community dependent, and are influenced by cultural norms and expectation.

2.2 Conceptualizing the Clinician-Patient Relationship

Respect involves recognizing patients as inherently valuable participants in the clinician-patient relationship. Respect in this clinical relationship is 'seeing' the patient as a person and conveys a moral obligation on clinicians (Beach et al., 2007). The following

section traces the role of respect in four conceptualizations of the clinician-patient relationship: paternalistic, clinician as perfect agent, consumerist and patient centered care.

The role of clinicians has evolved. The medical profession grew out of traditional medical healers, midwives and chemists who helped people who were sick, but were not scientifically trained. With the advent of medical schools, licensing exams, the American Medical Association (AMA) and internal self-regulation, physicians accrued a monopoly as providers of health services. The power of the medical profession in the United States continued to grow from the 1840s. They controlled the division of labor in health care without significant Government intervention and established legal and organizational dominance (Starr, 1982). Their power was consolidated in the 1940s when more people began to have access to health insurance and could choose to visit doctors for their healthcare needs (Pescosolido, Tuch, & Martin, 2001). The clinician-patient relationship has been described in various ways over time and the paternalistic, physician as perfect agent, consumerist and patient centered models that have emerged are shown in Table 1.

Table 1: Models of the Clinician-Patient Relationship and Respect

Model	Characteristics of Respect
Paternalistic	Clinician led encounter Patient respects clinician
Physician as perfect agent	Clinician led encounter Respect for patient's values and preferences

Consumerism	Patient led encounter Respect for clinician expertise
PCC	Clinician and patient engage in the encounter Patient and clinician are respectful

One of the earliest and most influential sociological works that contributed to our understanding of the clinician-patient relationship as paternalistic was Talcott Parsons' conceptualization of the sick role. Parsons argued that there is an institutionalized superiority in the relationship between health care agent and the ill person (Parsons, 1975). For Parsons, being ill is regarded as deviance from the usual societal norms and potentially undermines society because sick individuals cannot contribute as they did when well and are exempt from many social and productive responsibilities. Society accords both the patient and the clinician roles to improve the health of the sick person and promote social order. The sick role for the patient has 3 key criteria: (1) Illness is not the patient's fault, (2) It is understood that illness results in an exemption from ordinary daily obligations and expectations and (3) patients will seek help from "some kind of institutionalized health service agency" (Parsons, 1975). This relationship implies that the patient must respect the provider with no reciprocal obligation on the part of the clinician. The responsibility of the patient is to seek help and follow the clinician's guidance to return to his/her usual functions. The doctor's role is described through their fiduciary responsibility to the patient. Although Parsons discusses the ethical responsibility of the clinician to look after the ill person with the end goal that they can resume their usual

societal functions, there is no reference to respect in the doctor's role in the clinician/patient relationship. It is presumed that the clinician is competent, of high intelligence and morals; has the capacity to treat the patient, gained through clinical and scientific training as well as experience, and that the doctor is willing to accept this role and act in accordance with the best interests of the patient and that the patient should respect this expertise and inherent superiority of the clinician (Parsons, 1975). It is implicit that the patient should respect the clinician for their 'competence and authority' (Clucas & St Claire, 2010).

Critics of Parsons argue that clinicians may not be as objective as portrayed and that it is an oversimplification to suggest that physicians are motivated purely by the interests of the patients (Freidson, 1974). For example, McKinlay writes, "despite their 'objective' medical training, physicians remain human actors, socially conditioned to engage in stereotyping, whether consciously or not" (McKinlay, Potter, & Feldman, 1996, p. 769). Van Ryn and colleagues explore implicit biases that leads healthcare providers to contribute to racial and ethnic disparities; and conclude that experiences during medical school can influence clinician behaviors through implicit bias (van Ryn & Fu, 2003; van Ryn et al., 2015). Clinicians may also be motivated by other factors such as payment and financial incentives (Hajjaj, 2010). Characteristics of the patient, the clinician, and the healthcare system all shape the clinician's approach to decision making

(Eisenberg, 1979). Realizing that clinicians may not be as impartial as Parsons suggests in his paternalistic model of healthcare, research around the clinician-patient relationship began to consider the clinician as perfect agent.

The 'physician as perfect agent' model requires that the patient accept that the clinician will make medical decisions on their behalf (Gafni, Charles, & Whelan, 1998). The challenge for the clinician is to understand the many permutations of patient needs and preferences in individual contexts (Guyatt, 2002). This may prove to be difficult to accomplish as economists have realized that there is no such thing as 'perfect agency'. While this model does not address the issue of respect explicitly, it is assumed that for an individual to delegate authority for treatment decisions to another due to an asymmetry of information, they must respect that other's authority and expertise. It is also assumed that to be able to make the same choice as the patient would have made if they had the same knowledge as the clinician, then the clinician will need to respect the patient as a person to understand their individual needs, preferences and context (Gafni et al., 1998). This model has proven difficult to implement in practice, as it is easier to transfer evidenced based knowledge to patients than for clinicians to know all the needs and preferences of patients.

A third conceptualization of the clinician-patient relationship is consumerism. Structural changes including the way insurance has been organized, managed care

practices, and the move from individual practitioners to employees of larger hospital systems contributed to patients being seen as consumers of health care (Pescosolido et al., 2001). Pescosolido et. al further discuss the decline in confidence in social institutions, including medicine, that contributed to a consumerism movement in the 1990s.

The consumerist approach to the clinician-patient relationship emphasizes patients as rational entities with increased bargaining power, exercising choice in a free market (Applbaum, 2009; Beisecker, 1988; Lupton, 1997). The market establishes price and quality and clinicians sell their services to informed, rational consumers: patients who are on a more equal footing with clinicians, Fielding (1999) in (Clucas & St Claire, 2010). Patients must expend an unequal amount of social capital, compared to patients in other models of the clinician-patient relationship, to navigate health care in the consumerist model. This economic approach to healthcare services places more emphasis on the role of the patient in the clinician-patient relationship but does not discuss whether care should be delivered in a patient centered manner or not. Indeed, Clucas and St. Claire (2010) note that traditional (paternalistic) patients may feel more respected than consumerist patients, based on expectations (or lack thereof) of being treated with respect by clinicians (Clucas & St Claire, 2010).

However, neither the paternalistic, clinician as perfect agent, nor the consumer models can explain the entirety of the clinician-patient relationship. Patient perspectives

of the relationship vary. For example, in a study on age and consumerism, younger patients suggest that they would be more consumerist in their interactions, but in actual encounters their behavior did not reflect their preconceived ideas of how they would act (Beisecker, 1988). Beisecker concluded that age did not influence consumerism in the actual encounter as most patients behaved as traditional, Parsonian patients who are passive in their communication behaviors with clinicians (Beisecker, 1988).

Lupton further explores the complexity of the clinician-patient relationship after conducting in-depth interviews with 60 lay people in Australia. Lupton concludes that patients might embody the spectrum of roles accorded them in the clinician-patient relationship, from passive patients in a paternalistic relationship to consumers exercising choice (Lupton, 1997). In this important research, lay people were asked to discuss whether the status of medical professionals had changed over time and they agreed that it has. While respondents felt that clinicians are still respected *"the family doctor was someone you listened to and respected*", clinicians are more open to criticism now "*I think the community perception of doctors is a poor one*" (Lupton, 1997). Participants were asked to distinguish between 'good' and 'bad' doctors and some of the characteristics of 'good' doctors have also been attributed to respectful traits elsewhere in the literature, such as 'an ability to listen and communicate well' (Lupton, 1997). Although participants recognized the importance of bio-medical training, they also

acknowledged the importance of the clinician seeing them 'as an individual' (Lupton, 1997). Lupton concludes that the interaction between clinician and patient, tone, manner, and communication are all factors in the 'consumption' experience that will affect the outcome, especially in terms of satisfaction. One of the contributions of a consumerist approach to healthcare has been research around what is important to patients. The technical competence of clinicians is important but patients also care about interpersonal communication in their relationship with their clinician.

In the final analysis, neither a purely paternalistic nor a 'consumerist' approach to healthcare delivery describes most clinical encounters. Eisenberg (1979) argued that there is variety in clinical encounters from: (1) activity-passivity in which the clinician controls the relationship and the patient is passive (2) guidance-cooperation in which the clinician provides advice that the patient is expected to agree and comply with and (3) mutual participation in which the clinician helps the patient to help him or herself (Eisenberg, 1979). It is the third type of healthcare delivery that is increasingly emphasized as patient centered care (PCC). In terms of respect for the participants in the clinician-patient relationship, PCC explicitly respects patients' values and preferences.

2.3 Conceptualizing Patient Centered Care (PCC)

Patient centered care (PCC) has emerged within the last 10 years as an alternative to the paternalistic model of the clinician-patient relationship (Mead & Bower, 2000).

PCC is advocated as a means of improving healthcare delivery through a "more respectful, sharing and empowering approach of the patient" (de Haes, 2006). Through survey data, Reerink and Sauerborn revealed "that the perceived low quality of health care was one of the reasons why people did not attend primary health care services in cases of illness," (Reerink & Sauerborn, 1996). Low quality of care is further linked to the failure to receive appropriate or adequate care and may even result in harmful care (Barber & Gertler, 2008).

As shown in Table 2, there are a variety of definitions of PCC and many have at their core respect for individual patient's needs and preferences. The Institute of Medicine (IOM) envisages PCC as "a partnership among practitioners, patients and their families that facilitates decisions respecting patients' wants, needs, and preferences" (IOM, 2001). More recently, the ACA of 2010 is replete with references to patient centered care. For example, Subtitle F: Health Care Quality Improvement, Sec. 3502 Establishing community health teams to support the patient-centered medical home, Sec. 2717: Ensuring Quality of Care highlights 'patient-centered education', Part S: Healthcare Quality Programs, Sec. 399 highlights 'patient-centeredness of healthcare for all populations', Part D: Healthcare Quality Improvement, Sec. 931 Quality Measure Development includes references to patient-centeredness and in Subtitle D: Patient Centered Outcomes Research, Sec. 6301 the ACA authorized the Patient Centered

Outcomes Research Institute (PCORI) and funded it to the extent of $3 billion over ten years. PCORI seeks to fund research on evidence-based medicine, and shared decision-making among others.

In conjunction with the millions of dollars made available for research in these areas, there is an emergent literature on PCC, evidence, and SDM. While intuitively appealing, the concept of PCC is so multifaceted, that no single theory can be applied to its deconstruction (Ishikawa, Hashimoto, & Kiuchi, 2013). Given that there is much variation among researchers on the definition of PCC (Bertakis & Azari, 2012; Michie, Miles, & Weinman, 2003), de Haes calls for research to "disentangle the concept of patient centeredness" (de Haes, 2006) and Rathert et al. suggest that further research is needed to examine dimensions of PCC that "have not been studied extensively" (Rathert, Wyrwich, & Boren, 2013). In this regard, there is a need to consider the individual domains that make up the whole of PCC, particularly respect. Scholl et al. (2014) conducted a systematic literature review of articles containing definitions of PCC. They found that throughout the literature PCC was described as "fuzzy" or "poorly conceptualized" (Scholl, Zill, Harter, & Dirmaier, 2014). Through their analysis, the authors proposed an integrated model of patient centeredness that includes domains of principles, activities and enablers of patient centeredness at three levels, the micro (clinical encounter), meso (healthcare institutions) and macro (policy) levels. Included in

the core principles are characteristics of the clinician which include being respectful, empathic and compassionate and seeing each patient as a unique person in a broader social context. Patient centered activities include clinician-patient communication and respecting patients' information needs and preferences and patient involvement in care through SDM (Scholl et al., 2014). Per Scholl and co-authors, the 15 dimensions of patient centeredness that they outline are inter-related and not independent of each other.

Table 2: Dimensions of Patient Centered Care and Respect

Author	**PCC Dimensions/ Definitions**	**Respect (Implicit/Explicit/Neither)**
IOM Report 2001	A partnership among practitioners, patients and their families that facilitates decisions respecting patients' wants, needs, and preferences.	Explicit inclusion of respect
Int'l Alliance of patients' organizations 2012	Respect, choice and empowerment, patient involvement in health policy, information, access and support	Explicit inclusion of respect
Mead and Bower 2000	The bio-psychosocial perspective, the patient as person, sharing power and responsibility, the therapeutic alliance and the doctor-as-person	Implicit inclusion of respect
Epstein et al. 2005	(1) patients' needs, wants, and experience (2) allowing patients to participate in their care and (3) enhancing the clinician-patient relationship to improve quality of care.	Implicit inclusion of respect
Pulvirenti et al. 2012	A strategy for 'empowering patients to effectively critique and provide feedback on the quality and appropriateness of healthcare services'	Neither
De Haes 2006	To be respectful to patients, and thought of as paying attention to psychosocial issues, to stimulate autonomy and empowerment	Explicit inclusion of respect
Ferrer and Gill 2013	An approach to healthcare delivery based on "whole-person knowledge, *respect* for patients' preferences and fostering a productive clinician-patient relationship"	Explicit inclusion of respect
Rathert et al.	"Compassionate, empathetic and responsive" to	Neither

Table 2: Dimensions of Patient Centered Care and Respect

Author	PCC Dimensions/ Definitions	Respect (Implicit/Explicit/Neither)
2012:p.352	individual patients	
Berwick 2009: p.560	"Transparency, individualization, recognition, *respect*, dignity and choice in all matters…"	Explicit inclusion of respect
Scholl et al. 2014	Systematic review of definitions of PCC resulting in 15 dimensions including characteristics of the clinician, clinician-patient relationship, patient as a unique person, biopsychosocial perspective, communication, access to care, continuity of care, patient information, involvement in care, and empowerment.	Explicit inclusion of respect

Many of the definitions and descriptions of PCC explicitly include respect for patients as a fundamental principle, or implicitly include respect in their references to the patient as person, psychosocial perspectives and incorporating patient's needs and preferences in the clinical encounter. Sharing of information is also used to describe patient centered care. Indeed, within the literature, PCC is often operationalized as shared decision making (Barry & Edgman-Levitan, 2012).

2.4 Conceptualizing Shared Decision Making (SDM)

There are varying definitions of shared decision making (SDM) within the scientific literature. Like the clinician-patient relationship, SDM has evolved over time. SDM was originally described as clinicians sharing technical information, based on the best available medical evidence, so that patients "are supported to consider options, to

achieve informed preferences" (Elwyn et al., 2012). In this informed decision model, SDM involves a patient and a clinician working together to reach a mutually agreeable treatment decision (Charles, Gafni, & Whelan, 1997). In practice, however, the extent to which patients are involved varies (Pulvirenti, 2011; Veroff, Marr, & Wennberg, 2013). Accordingly, recent descriptions of SDM have tried to outline a more collaborative and conversational based SDM where patients and clinicians work together to best address care within the patient's personal context (Kunneman et al., 2016).

The justification for SDM has also been described in various ways. SDM is ethically the right way to deliver care (Elwyn et al., 2012). It has also led to a reduction in practice variation (Stiggelbout, 2012) and can potentially affect other outcomes such as knowledge, satisfaction and cost (Gulland, 2011; McCay, 2010; Oshima Lee & Emanuel, 2013; Veroff et al., 2013). In this study, the moral justification for SDM mirrors a social justice justification for respect, whereby a patient feeling respected "is desirable in and of itself and may mitigate a person's distress associated with illness and uncertainty" (R. M. Epstein & Street, 2011). It seems intuitive that respect is an important aspect of the clinician-patient relationship that is necessary for both patients and clinicians to benefit from SDM healthcare delivery. There is space within the literature for further research on the significance of respect for SDM, and it is this gap that this study aims to fill.

What is SDM?

In earlier models of SDM, Charles and colleagues established minimum conditions that should be met for the decision making to occur. SDM involves at least two people, a patient and a clinician who partner and both share information (Charles, Gafni, & Whelan, 1999). Together the doctor and patient should agree on a decision that they are both comfortable with (Elwyn et al., 2000; de Haes, 2006). Where there is more than one viable course of treatment, SDM has the potential to better align agreed upon care with patients values and preferences (Oshima Lee & Emanuel, 2013). Clayman and colleagues have sought to reconceive of SDM as centering 'on the person' and their broader personal context instead of the medical encounter (Clayman, Gulbrandsen, & Morris, 2016). This view was presented earlier by Hargraves et al. so that SDM would be about 'conversations and care' not just information and choice (Hargraves, LeBlanc, Shah, & Montori, 2016).

Why is SDM used in practice?

Implementing SDM can affect patient reported outcomes such as patient satisfaction and compliance (Gulland, 2011), reduce practice variation (Stiggelbout, 2012) and increase knowledge, perceptions of risk and benefits, decisions based on patient's values and fewer passive or undecided patients (Hess et al., 2012; Montori et al.,

2011; Weymiller et al., 2007). While the use of Decision Aids (DAs) is not equivalent to SDM, the use of DAs is often cited in studies linking SDM to outcomes such as increased knowledge, understanding the benefits and harms of treatment options, making choices that reflect patient's values, increased participation in decision making, increased patient satisfaction with the decision-making process, improved patient-clinician communication, and a reduction in decisional conflict and choice of major elective invasive surgeries in favor of more conservative options (Shay & Lafata, 2015; Stacy et al., 2014). In this regard, other studies have demonstrated that SDM can decrease costs, particularly for invasive surgical procedures (McCay, 2010; Oshima Lee & Emanuel, 2013; Veroff et al., 2013). For example, a study by the National Academy for State Health Policy suggests that "an initial cost analysis of implementing SDM for 11 procedures estimates the savings to national health spending to be greater than $9 billion over ten years", (Shafir & Rosenthal, 2012). The cost savings estimate is based on an earlier analysis done by the Lewin Group for the Commonwealth Fund, (Lewin Group *Bending the Curve*, 2008). These researchers based their estimations on the results of numerous studies which piloted decision aids for prostate cancer screening, menorhaggia, coronary revasculization for angina, prostatectomy, stroke prevention, mastectomy and lumber spine surgery for back pain. The studies concluded that the prevalence of invasive procedures was reduced and the savings are a result of the relative cost of alternate

procedures. The Lewin Group used Medicare claims data to establish a baseline expenditure for the procedures in the pilot studies and established the cost of increased utilization of alternative treatments (as seen in pilot studies using decision aids) plus the cost of invasive procedures post the intervention with decision aids and estimated a savings compared to the pre-intervention costs. Costs savings are often cited in earlier literature on the benefits of using DAs but these results have been contested in more recent studies and systematic reviews (Walsh, 2014). One of the reasons cited is poor quality of the evidence used to justify savings at a system level. Another argument is that longer follow-up periods are needed (Walsh, 2014). In instances where patients make more conservative decisions about invasive surgical procedures, they may revisit these decisions overtime with a resulting cost to the healthcare system that could not be foreseen at the time of the initial study (Walsh, 2014). It is also important to look beyond the outcomes reported in previous studies and to acknowledge the ethical underpinnings of shared decision-making. According to Glyn Elwyn, a leading proponent of shared decision making, SDM should be practiced because it is the 'right thing to do' (Elwyn et al., 2012).

How is SDM practiced?

Despite its capacity to operationalize patient centered care (Barry & Edgman-Levitan, 2012), SDM is not routinely implemented in practice (Stiggelbout, 2012). In the patient-centered relationship model, the clinician with expert medical knowledge and the patient with expertise in their personal contexts and daily management of chronic conditions are both experts in the encounter. Ideally SDM would harness this expertise and be practiced such that there is a flow of information between the participants in the encounter. Decision Aids (DAs) are often used to prepare either the patient or the clinician for the encounter and can be useful prior to decisions being made (Kunneman et al., 2016). DAs are also used in some instances to facilitate the exchange of evidence based clinical information and patient values and preferences in the encounter. Some DAs are widely used in practice, with one recent study showing that there are 12,000 online instances of their decision aids being used every month (Kunneman et al., 2016). While this is encouraging for SDM in practice, DAs are a tool to facilitate SDM and do not equate to SDM in and of itself (Kunneman & Montori, 2016). DAs can be pamphlets, videos, or decision cards derived from scientific evidence to portray the risks and benefits of treatment options. It is important to note that even the design and application of decision aids varies (Tiedje et al., 2013). Many DAs are designed as information tools to be accessed by patients prior to the encounter (Stiggelbout, 2012), while others are designed to be used within the encounter (Branda et al., 2013; Montori et al. 2011;

Mullan et al., 2009; Weymiller et al., 2007). Studies on DAs have shown that barriers to their effective use include unfamiliarity, inadequate training and potentially additional time for the encounter (Friedberg, Van Busum, Wexler, Bowen, & Schneider, 2013; Legare, Ratte, Gravel, & Graham, 2008).There are also competing discussions on the benefits of using DAs in instances where patients have low levels of health literacy. One argument is that clinicians may use DAs to convince or bargain with patients that their perspective is correct (Tiedje et al., 2013). A competing belief is that the use of DAs in the encounter may overcome the challenges facing patients with low health literacy as they are not left to wade through information on their own, but can engage in discussions with clinicians in real time on the evidence being shared (Kunneman et al., 2016; Stiggelbout, 2012). What we should realize is that although the ACA calls for SDM to be implemented to improve quality of care, it should not be implemented solely as the use of DAs (Durand, Barr, Walsh, & Elwyn, 2015). Incentivizing the use of DAs runs the risk of not measuring the communicational aspects of SDM (Durand et al., 2015). The argument for SDM as engaging in a conversation, "a conversational dance", within the encounter is gaining prevalence in the SDM literature (Kunneman & Montori, 2016). SDM has the potential to improve quality of care by putting patients at the center of their healthcare (Stiggelbout, 2012) and by engaging in kinder, more careful care for that individual patient at that time, as opposed to care for all people like that patient (Kunneman &

Montori, 2016; Kunneman et al., 2016). The conversational model of SDM may alleviate some of the outlined barriers to participation (Joseph-Williams, Elwyn, & Edwards, 2014). Engaging in a conversation may reduce the power imbalance in the encounter while facilitating information flow. What it cannot do is address some of the reported institutional barriers such as time, workflow, continuity of care and the healthcare system characteristics that are out of the clinician and patients' control (Joseph-Williams et al., 2014).

2.5 Conceptualizing Respect in Healthcare

Healthcare is one of Rawls' essential primary social goods (Denier, 2005). Within healthcare, respect is described similarly to Rawls' social justice framework, as 'the inherent value of patients as persons' (Beach et al., 2007; Darwall, 1977; Green, 2010; Morris, 1997). 'Recognition respect' is realizing that patients are deserving of respect and should be taken seriously as they deliberate what to do, and say about their healthcare (Darwall, 1977). Essentially, patients are deserving of respect and their capability to utilize resources should also be respected (Nussbaum, 2011).

How clinicians demonstrate respect is often described through clinician attitudes (Beach et al., 2006) and respect is credited as the first step in establishing communication between the clinician and the patient (Frosch & Tai-Seale, 2014). The Clinician and Group Consumer Assessment of Healthcare Providers (CG-CAHPS) is an annual survey

that asks patients to evaluate their healthcare experience. One of the survey questions asks whether the clinician 'shows respect' in their communication. This may be an ambiguous item as it is largely a matter of patient perception of what 'respect' is. However, Frosch and Tai-Seale (2014) note that 'given the intuitively indisputable importance of respect in collaborative human relationships, some general principles of what constitutes treating someone with respect should be deducible'.

Defining and measuring respect is challenging as it means different things in different circumstances with different patients. This has led to respect being described as a vague concept (Spagnoletti & Arnold, 2007). Respect may also be culturally specific. For example, making eye-contact is deemed respectful in a Western culture, but may be difficult for some patients, such as Navajo Indians. Indeed, for some populations, discussing bad news or a fatal prognosis is believed to be associated with adverse consequences, including death (de Haes, 2006). Green notes that symbolic gestures of respect are context specific and changing, thus identifying and measuring how respect is shown, offered and received may be problematic (Green, 2010). Respectful environments and processes such as adequate waiting rooms, seating, bathrooms and other facilities for patients' physical comfort; clinicians not being limited by time, privacy in encounters, prompt appointment times all constitute what might be understood as offering a respectful service. The absence of respect, disrespect, has been credited with causing

'incivility and polarization between individuals' (Schwalb & Schwalb, 2006).

Within the literature, the definition used by Beach et al. (2007), captures respect as closely as this study conceives of the term. Simply put, it is understood as "a recognition of the unconditional value of patients as persons" (Beach et al., 2007). Woodruff supports this Kantian view of respect as a moral obligation to "each other for our value as human beings" (Woodruff, 2013). This recognition is irrespective of patient characteristics and should therefore be applied to all patients. It is also separate from respect for autonomy or the patient's ability to communicate their preferences and decisions within the encounter. It begins even before this stage, at the point of the patient being present, and requires "only an acknowledgement of the patient as person" (Beach et al., 2007). For the authors of this important contribution on the meaning of 'respect' it is both a cognitive notion, believing in the value of patients as well as a behavioral one, acting on the belief of the value of the patient (Beach et al., 2007).

2.6 Terminology synonymous with respect within the literature

Empathy, admiration, esteem, high regard, deference, humanized care and dignity are often used interchangeably with respect (Browne, 1993). These concepts are used, as is respect, to highlight the need for clinicians to focus beyond the clinical diagnosis and to take the patient's context into account. If not, clinicians may "cause a patient harm by

delivering treatment that is not sensitive to the totality of the patient's needs" (Bayne et al., 2013). In conceptualizing empathy, Bayne and colleagues describe it as an important factor in the clinician patient relationship that is now included in medical education to emphasize whole person care. Yet, most of the evidence for including empathy was based on quantitative studies without a definition of empathy. Bayne et al. sought to understand how clinicians describe empathy and found that there are varying degrees of empathy and that certain conditions encourage its presence more than others; these can be internal to the clinician or systems directed. Many of the descriptions of "genuine empathy" mirror understandings of respect in the literature such as caring, compassion, understanding, and person centered care (Bayne et al., 2013). Depending on the conceptual definitions of these terms, they can also be viewed as domains of patient centered care.

Indeed, in some studies, definitions of dignity include respect. For example, in her treatise on dignity and respect for dignity Gallagher highlights that dignity can be viewed subjectively and is different for different individuals. Some authors suggest that 'respect and dignity can only be measured by knowing what these terms mean to the patient' (Gallagher, 2004). Dignity can also be viewed objectively and apply to all equally by virtue of being human (Gallagher, 2004). Further studies highlight dignity framed within the context of respect, staff having a "professional duty to respect patients' dignity" (Baillie, 2009), "the principle of human dignity calls for respect of each individual as

unique" (Berglund, Anne-Cathrine, & Randers, 2010) and as "respecting human dignity" or "respect for their humanity and dignity" (Manookian et al., 2014). Furthermore, Manookian and colleagues conducted a qualitative study 'to explore the factors that comprise patient dignity' and found that many of the factors relate to respect. For example, when patients were asked to explain situations in which their dignity was respected or threatened they replied, "I must respect myself to be respected by others (Participant 3)"; "they didn't take into account that the patient is a human being. They should reply to his questions respectfully (participant 10)"; "I always try to treat others respectfully (Participant 13)"; "She respected my feelings and emotions (Participant 11)" and "I think this means respect toward human consciousness (Participant 8)" (Manookian et al., 2014, pp. 326-328). Similarly, in a study by Baillie, dignity comprises feelings such as being comfortable, in control and valued and rests significantly on respecting patient privacy. While patients can be responsible for their own dignity, it was understood that staff behavior could also affect whether patients had dignity or not (Baillie, 2009) . Beach et al. analyze the results of survey data on two measures of respect, 'involvement in decision making' interpreted as being associated with autonomy and a "broader" measure of respect, 'treatment with dignity' (Beach et al., 2005). This lack of conceptual clarity can be confusing and as such, it is important to bear in mind that although intertwined with research on dignity, respect is a unique concept that has moral and ethical

underpinnings as outlined previously. Respect encompasses the right of a patient to be regarded as a person and what this means to individual patients can be explored by engaging patients in research directly.

Finally, in the context of 'professionalism', private medical associations include respect for patients as part of their code of conduct. The 'American Board of Internal Medicine's Medical Professionalism in the New Millennium: A Physician Charter' highlights "respect for patient autonomy" and "respect for others is the essence of humanism, and humanism is both central to professionalism and fundamental to enhancing capacity among physicians" (Spagnoletti & Arnold, 2007). Although respect is included in these charters, it is not clearly defined and therefore practical implementation of the concept remains problematic.

2.7 Studies in the literature on Respect in Health Care

Table 3 reviews studies that have examined respect in healthcare settings. The overwhelming view from these studies is that there continues to be a need for further research on the concept of respect within the clinical encounter (Beach 2005, Beach et al. 2006, Joffe et al.2003, Clucas et al. 2010, Koskenniemi et al. 2012, Browne 1993). These studies have been categorized according to three policy-related themes: (1) clinician-patient relationship (2) quality and (3) outcomes. Some studies included multiple

dimensions of respect and are included in more than one theme. The discussion that follows also includes the limitations of the respect studies.

Table 3: Studies of respect (by policy-related theme)

Author	Study Aim	Design	Findings
Clinician – patient relationship/ communication			
Beach MC, et al. (2005)	The positive effects of treating patients with respect broadly defined as dignity	Commonwealth Fund 2001 Health Care Quality Survey associations between two measures of respect (decisions and dignity) and patient outcomes (satisfaction, adherence, optimal preventive care)	Satisfaction was higher for treated with dignity and for those involved in decision-making. 76% responses treated with a great deal of respect and dignity. *Need research on a measure of respect*
Beach MC, et al. (2006)	Variability of physician-reported respect for patients	215 audio-taped patient-physician encounters; analyzed by (RIAS); Self-rated levels of perceived respect	Ratings of respect vary across patients, and are associated with familiarity and age. *Need research on a measure of respect*
Gudzune KA, et al. (2012)	Accuracy of obese patients' estimations of physicians' level of respect	Replicated Beach 2006 study; survey question on respect, socio-demographic data. Audiotapes of encounters with 39 MDs and 199 patients. RIAS analysis	Patients overestimate clinician's respect as BMI increases. Patients may be desensitized to disrespectful behaviors. *Study limitation - respect is nuanced - raters, coders, MDs, patients may have been using different conceptualizations of respect.*
Dickert and Kass (2009)	To understand patients' conceptions of respect	Semi-structured interviews with 18 survivors of sudden cardiac death at an academic cardiology clinic	Patients believed that respecting persons includes: empathy, care, autonomy, information, recognition of individuality, dignity and attention to needs. Respect is broader than autonomy.
Bendapudi et al. (2006)		Telephone interviews with 192 patients seen in 14 medical specialties at Mayo Clinic Arizona and Minnesota. Descriptions of best/worst	Ideal physician is confident, empathetic, humane, personal, forthright, respectful and thorough.

Table 3: Studies of respect (by policy-related theme)

Author	Study Aim	Design	Findings
		experiences with physicians were elicited.	
Arborelius et al. (1992)	To describe patients' experiences with general practitioners (GPs)	46 video-taped consultations at 4 Swedish primary care centers. Patients commented on the recordings	Clinicians viewed as a person who treats patients as equals. Interventions are framed by patients within the concept of whether the GP treated them with respect.
Respect and quality			
Quigley DD, et al. (2014)	Relation between five aspects of communication to overall ratings by physician specialty	Correlations of 28 specialties and 5 communication items; data from CAHPS 2005-2009	MD showing respect was most important aspect of communication for 23/28 specialties
Pescolido et al. (2001)	To compare the public's attitudes over a 20-year period	1976 National Survey of Access to Care and the 1998 General Social Survey.	Public attitudes toward physician respect for patients became more negative over time (51% agreed physicians always treat their patients with respect vs. 67% in 1976)
Joffe S, et al. (2003)	Influence of decision making, confidence, trust and treatment with dignity and respect on patients' evaluations of hospital care	680 patient survey responses	Treatment with respect and dignity and confidence and trust in providers is more strongly associated with willingness to recommend hospital than SDM; 85% always reported receiving respectful, dignified treatment
Morris NM, (1997)	Define and measure respect to evaluate quality of care in managed care settings	Clinical Observation Record Checklist includes communication items plus satisfaction surveys to provide external validity for COR.	Variability in respect scores over clinics and individual items. In the patient satisfaction survey, the open-ended questions had a high non-response rate; satisfaction scores may be skewed because socially undesirable to admit a dissatisfaction. Findings used to improve quality of care (e.g. less waiting times) in managed-care settings.
Browne, A.	Define respect in	Literature review	Respect is a primary nursing

Table 3: Studies of respect (by policy-related theme)

Author	Study Aim	Design	Findings
1993	the nursing literature		ethic. *Further research necessary.*
Koskenniemi J., et al. (2012)	To describe the experiences of older patients and their next of kin with regards to respect in the care given in an acute hospital.	Tape-recorded interviews of 10 patients and 10 next of kin were analyzed via inductive content analysis.	Respect can be defined by nurses' actions (politeness, patience, reassurance, response to info needs, assistance, provision of pain relief, responses to wishes and time management) and the environment (societal appreciation of the elderly, management of healthcare organizations, nursing culture, flow of info and patient placement). Patients' right to be cared for with respect. *Need for more studies on respect.*
Valentine et al. (2008)	The importance of eight domains in the WHO non-clinical quality of care concept 'health systems responsiveness'	105,806 survey interview records from WHO's general population surveys in 41 countries. 'Respect for persons' included: Dignity (being shown respect; physical exam in private); autonomy (involved in care and treatment decisions); confidentiality (of info and private talks with clinicians)	41% of respondents selected prompt attention (geography and emergency access) as the most important domain followed by 22% choosing dignity and 14% choosing communication. Internal validity was obtained as prompt attention and dignity were least selected as the least important (4 and 3%). Dignity related to humaneness of treatment.
Beach et al. (2007)	Conceptually definition of respect with a moral obligation on physicians	Discussion paper	Respect involves valuing patients by extending common courtesies, concern for others, taking feelings seriously
Bergseiker et al. (2010)	Relationship between racial representations and management goals in interracial interactions	Literature Review	Racial minorities seek to be respected and seen as competent more than Whites who seek to be liked.
Barnard et al (1995)	Settings for teaching religious	Discussion paper	Teaching values to medical students is an opportunity to

Table 3: Studies of respect (by policy-related theme)

Author	Study Aim	Design	Findings
	issues in medicine		practice person-centered medicine and respect individuality of patients
Outcomes			
Clucas, C and St. Claire, L (2010)	Effect of respect on patient outcomes and influence of patient identification with a traditional or consumerist patient role	87 Participants, recruited through a convenience snowballing sample in the UK. 2x2 design pt. role (traditional or consumerist) and doctor behavior (respectful/ disrespectful). Vignettes followed by survey. Patients rated 'how respected they felt'	Role-playing where doctor's behaviors were respectful reported greater patient satisfaction, adherence and likelihood of revisiting the doctor.
Beach MC, et al. (2005)	The positive effects of treating patients with respect broadly defined as dignity	Commonwealth Fund 2001 Health Care Quality Survey associations between two measures of respect (decisions and dignity) and patient outcomes (satisfaction, adherence, optimal preventive care) (satisfaction, adherence, optimal preventive care); stratified results across racial/ethnic groups	Being involved in decisions associated with adherence for whites, treated with dignity was associated with adherence for racial/ethnic minorities. Being treated with dignity and involved in decisions are independently associated with outcomes. *Need research on a measure of respect*
Blanchard J, Lurie N. (2004)	Examine factors in the health care encounter to model how negative perceptions of the encounter influence HC utilization	Commonwealth Fund 2001 HC Quality Survey, 6722 adults; measures included being treated with disrespect	Minorities are significantly more likely to report being treated with disrespect; Perceptions of being treated with disrespect affect utilization and contribute to existing disparities
Beattie et al. (2007)	To test the reliability and validity of a Spanish language version of the MedRisk Instrument for Measuring Patient	A 20-item MRPS survey was completed by patients after outpatient physical therapy care.	"My therapist treated me respectfully" as a global measure of satisfaction scored 4.8 on a scale of 1-5. Spanish language survey is reliable and valid and like the English version, patient satisfaction is linked to physician's behavior.

Table 3: Studies of respect (by policy-related theme)

Author	Study Aim	Design	Findings
	Satisfaction With Physical Therapy Care (MRPS).		
Beyene et al. (2011)	Assess the quality of healthcare in the Jimma region, southwest Ethiopia	640 patients and 96 care providers. An interview questionnaire and an observational checklist to assess quality of care as structure, care process and satisfaction.	Satisfaction was high for patients (89.1%) and care providers (86.7%). Respect given to patients by providers was poor. Providers (48.2%) were viewed as low performing.

(1) Respect and the clinician-patient relationship

As seen in Table 3, respect in healthcare is mostly framed within the context of the clinician-patient relationship and is linked to communication behaviors in clinical encounters (Beach et al., 2006; Beach et al., 2005; Gudzune, Huizinga, Beach, & Cooper, 2012; Pescosolido et al., 2001; Quigley et al., 2014). The studies done by Mary Catherine Beach and colleagues at Johns Hopkins (Beach et al., 2006; Beach et al., 2005; Gudzune et al., 2012) stress the role of respect in improving clinician-patient communication. Data from a large Commonwealth Fund survey was analyzed with results showing that 76% of respondents felt that they were treated with a great deal of dignity and respect. Being treated with respect was broken down into two components, treated with respect and dignity and involved in decision-making. In this study, respect for persons is asked as 'did the doctor treat you with (a great deal of) respect and dignity' and is a broader

definition than respect for autonomy phrased as 'did the doctor involve you in decisions about your care?' The authors concluded that being treated with dignity and respect is an independent concept from being involved in decision making, and that both are important. They argue that respect is broader than autonomy (decision making), it also encompasses 'regarding the patient as having inherent value' (Beach et al., 2005). Dickert and Kass (2009) drew similar conclusions on respect as broader than autonomy, with patients describing 'recognition of individuality and dignity' as conceptual components of respectful clinician behaviors (Dickert & Kass, 2009).

In a further study by Beach and colleagues, post-encounter surveys were distributed to patients and physicians that elicited information on "Compared to other patients, I have a great deal of respect for this patient" and "This doctor has a great deal of respect for me". The clinician responses varied, with physicians strongly agreeing that they had respect for 34% of patients, agreeing for 45% and neutral or disagreeing for 21%. Respect was not associated with race concordance or clinician and patient characteristics but was associated with familiarity. Forty-five percent (45%) of patients overestimated clinician respect for them (Beach et al., 2006). Two hundred and fifteen (215) audio-taped clinical encounters were analyzed for communication behaviors, using four measures (information-giving, rapport building, verbal dominance and global affect) of the Roter Interaction Analysis System (RIAS), a validated coding system for clinician-

patient communication. Beach et al. conclude that information giving (patient education and counseling statements) and positive affect (interest, friendliness, responsiveness and sympathy) demonstrate more respectful providers. The authors state that physician attitudes of respect may be important for improving communication with patients (Beach et al., 2006). In replicating the Beach et al. study of 2006, Gudzune and colleagues analyzed audiotapes of 39 clinicians and 199 patients to understand communication behaviors in the clinical encounter. They also analyzed survey questions comparing clinician and obese patients' levels of respect and concluded that obese patients themselves may be desensitized to disrespectful behaviors, particularly where they overestimate clinician's respect for them, 37% of patients did so. The authors found that 'for each 5kg/m increase in BMI the odds of overestimating physician respect significantly increased' (Gudzune et al., 2012). The authors conclude that the misperception of respect suggests 'inauthentic relationships' (Gudzune et al., 2012) and this could affect the quality of the clinician-patient relationship. Inauthentic communication becomes an issue when clinician communication is reduced to a checklist and does not involve 'empathetic connections' with patients. They question whether the clinician can incorporate the patients' best interests if they do not respect them (Gudzune et al., 2012).

Other research has directly examined whether communication and respect are linked to patient satisfaction. In a recent study, Quigley et al. sought to establish what aspects of physician communication are associated with overall physician ratings by clinical specialty. The data is from CAHPS 2005-2009 data of 58,251 adults and 534 physicians. For 28 clinical specialties, the authors calculated partial correlations of five communication items (how often the physician: explains things, listens carefully, gives easy to understand instructions, spends enough time and shows respect) with overall physician rating, controlling for patient demographics. The authors conclude that the item 'how often the clinician shows respect' was the most important aspect of communication in the clinical encounter for 23/28 of the specialties. Other factors vary by specialty, but all patients valued respectful treatment (Quigley et al., 2014).

Pescosolido et al. highlight the issue of respectful attitudes as important in describing the clinician-patient relationship. They compared national survey data gathered in 1976 with national survey data from 1998 to demonstrate this. Within the survey, there is one question specifically addressing respect, "Doctors always treat their patients with respect." The researcher found that the percent of respondents who agreed with that statement decreased from 67% to 51% between 1976 and 1998 (Pescosolido et al., 2001). Those patients without health insurance and in poorer health were the ones most likely to respond that their doctors do not always treat them with respect.

Finally, Bendapudi et al. report that the ideal physician is 'respectful' according to telephone interviews with a random sample of 192 patients seen at Mayo Clinic Rochester and Arizona (Bendapudi, Berry, Frey, Parish, & Rayburn, 2006) and incorporating these attitudes and behaviors in clinical care can lead to a more positive perception of the clinician-patient relationship by patients. This view is echoed by Arborelius et al. who delineate the 'good' from the 'bad' GP and note that treatment interventions are perceived within the frame of whether the clinician treats the patient with respect (Arborelius, Timpka, & Nyce, 1992).

(2) Respect and Quality of Care

As shown on Table 3, several studies have identified respect as a measure of evaluating hospital care. For example, Joffe et al. (2003) note that respect is a significant measure influencing patient evaluations, even more so than shared decision-making. The authors analyzed 680 patient responses, with 85% of respondents reporting that they always receive respectful, dignified treatment. The authors conclude that being treated with respect and dignity is strongly associated with a willingness to recommend a hospital (Joffe et al., 2003). Similarly, Quigley et al. conclude their study on clinician-

patient communication by suggesting that quality improvement efforts should emphasize clinicians showing respect to patients (Quigley et al., 2014).

In another study aimed at evaluating the quality of care, Morris (1997) developed a measure of respect through which she could compare clinics on the amount of respect shown to patients. The aim was to observe clinician-patient interactions to evaluate the quality of care evidenced in managed care settings (Morris, 1997). In order to employ respect as a quality measure, Morris defines respect as a behavior that "accords the patient high status in a sociological sense" (Morris, 1997). In using this definition, the authors acknowledge that clinicians treat patients of varying socioeconomic status differently. They compared the care received at private obstetric clinics in middle-class communities with public hospitals, by measuring the degree of respect evident in behaviors and the physical environment (Morris, 1997). Measures used by Morris and her team to evaluate respect formed part of the Clinical Observation Record (COR) and included: whether staff ignored patient on arrival, introduced themselves to the patient, asks permission for an observer to be present, how provider addresses the patient, tone of voice used, shared information, explained treatments, time left waiting in the observation room, provides opportunities for patients to ask questions, answers patients' questions, uses biased or value statements, interruptions, discussion among medical team in front of patient, direction on follow-up and length of visit (Morris, 1997). The physical aspects of

the clinic/hospitals were rated according to patient's privacy, arrangements for after-hours emergencies, and provisions for the patient's comfort: space, seating, lighting, reading materials, restrooms, atmosphere, play areas for kids and so on (Morris, 1997). Morris and her team developed respect measures after visiting clinics to view firsthand conditions and to speak with patients about their experiences. The author is upfront that patients' perspectives on respect were not always concordant with the critical observation of the team. Points were assigned, more points for more positive behaviors, and a total number of points calculated. The total score for each clinic was divided by the maximum number of points possible to determine a value of respect from zero (no respect) to one (full respect) (Morris, 1997).

Like Morris and her colleagues, others have looked at respect as a component of quality care. Browne deems respect to be a fundamental ethic of nursing care, particularly by respecting human dignity, autonomy and accepting a patient's value and uniqueness (Browne, 1993). Browne attempts to clarify the concept of respect by reviewing the existing literature. She notes references to respect as a 'central moral attitude from which all other moral principles are explained' (Downie and Telfer 1970), as a human value (Rokeach 1979), as the core of human rights (McDougall et al. 1980) and as 'an attitude necessary for justifiable ethical actions between people' (Browne, 1993). The characteristics of respect that Browne highlights are 'non-verbal messages, conveyed

through facial expressions, eye contact, touch, posture and relative positioning' of clinician and patient within the visit; 'verbal messages conveyed through tone of voice, how patients are addressed, interest shown as well as expressions of honesty and acceptance' and allowing 'patients to make choices' (Browne, 1993). Browne suggests that the challenge now exists to teach respect to nursing students and professionals (Browne, 1993).

Finally, Koskenniemi et al. interviewed 10 patients and 10 next of kin from a sample of Finnish elderly patients who had undergone hip surgery, to determine whether they felt the nursing care they received in an acute hospital setting was respectful (Koskenniemi, Leino-Kilpi, & Suhonen, 2013). The authors note that the physical environment as well as nurses' actions (politeness, patience, reassurance, responding to information needs, assistance with basic needs and time management) can denote respect. Descriptions such as "Words are not so important… what is seen in a human being is more important" by a 92-year-old patient demonstrates the concept of respect as recognizing the value of the person (Koskenniemi et al., 2013, p. 8). The results of this study could be used to realize 'respect in the care of older patients in acute hospitals' as well as to inform practitioners that respect should be the basis of their 'orientation towards patients' (Koskenniemi et al., 2013, p. 15).

In summary, clinician attitudes, behaviors, attributes and dress are all described as linked to respectful (Au, Stelfox, & Khandwala, 2011) or disrespectful care (Alexander, 2004; Amy, Aalborg, Lyons, & Keranen, 2006; Anderson & Wadden, 2004) and are associated with communication (Beach et al., 2006), partnership (Bidmead & Cowley, 2005) and the strength of the clinician-patient relationship (Bjoerkman, Hansson, Svensson, & Berglund, 1995). Others see respect as indicative of the overall quality of care experienced (Alaloola & Albedaiwi, 2008; Allen, Creer, & Leggitt, 2000; Badeau, 2009; Baker, Hayes, & Fortier, 1998).

There was also an ethical dimension to respect inherent in quality care**.** Respect is discussed within the literature as it relates to autonomy (Barilan & Weintraub, 2001) and informed consent and is viewed as a moral obligation for clinicians delivering healthcare (Andersson, 1996; Beach et al., 2007). Some articles continue to argue that respect is more than autonomy especially as it relates to patients with severe illnesses (Beste, 2005). Perceptions of respect were nuanced among racial groups in one study with whites seeking to be liked and seen as moral as opposed to racial minorities who wanted to be respected and viewed as competent (Bergsieker, Shelton, & Richeson, 2010). Many patients consider themselves religious. Understanding how religion factors into patients' lives can increase understanding of patients' values and meaning toward their illness (Barnard, Dayringer, & Cassel, 1995). Articles that address religion in clinical encounters

note that it encourages respectful quality care by respecting the individuality of the patient (Barnard et al., 1995).

(3) Respect and outcomes

Within the literature there are several studies that examine respect and outcomes. In one such study, Clucas and St. Claire look at the effect of respect on patient outcomes by presenting 87 participants with hypothetical clinician/patient scenarios. The vignettes were either portrayed as traditional (cooperative, obedient, passive and unquestioning) or consumerist patients (purchaser of services, challenges physician authority and contributes to medical decision-making) and either respectful or disrespectful clinician behavior. (Dis)respectful behaviors were observed as gathering info about the illness by taking/not taking the patient seriously; diagnosing the condition by providing/not providing information; giving advice treating/not treating the patient as an equal and writing a prescription involving/not involving the patient in the decision. The scenarios where clinician behaviors were more respectful correlated with survey responses of outcomes of higher patient satisfaction, adherence and the likelihood of revisiting the clinician. They conclude that respect should be considered when attempting to predict patient health outcomes (Clucas & St Claire, 2010).

Similarly, Beach et al. in an earlier study had evaluated the association between

respect and patient outcomes such as satisfaction, adherence and preventive care. The study found that there is a greater probability of reporting high levels of satisfaction, adherence to therapy and receipt of optimal preventive services if patients perceive that they are treated with respect than not treated with respect. However, after adjusting for demographic characteristics, only satisfaction was significantly associated (Beach et al., 2005). Like the study by Beach et al., respect and respectful care are used to measure satisfaction with providers in surveys that question whether your clinician "treated me respectfully" (Beattie, Nelson, & Lis, 2007). In one instance, a high global rating of satisfaction with care did not predict satisfaction with the human aspects of care as "respect given to patients" was rated poorly (Beyene, Jira, & Sudhakar, 2011).

Finally, Blanchard and Lurie studied the impact of disrespectful treatment on utilization and disparities. They revealed that persons from minority groups are significantly more likely to report being treated with disrespect; and that patient perceptions of disrespect affect utilization and contributes to existing disparities in healthcare (Blanchard & Lurie, 2004).

Limitations of the Studies

Many of the studies in Table 3 acknowledge that there are three main limitations in researching respect in healthcare. Firstly, some of the studies rely on data in which

positive response rates to surveys may indicate a socially desirable response bias. In one study, as many as 85% of respondents report always receiving respectful and dignified treatment (Joffe et al., 2003). In another study, 76% of respondents state that they are treated with a great deal of respect and dignity (Beach et al., 2005).

Secondly, there are very few studies that have sought to use a validated measure of respect. Most studies have relied on single item survey questions on respect, which may not capture the complexity of respect as a concept. The result is a lack of conceptual clarity on the meaning of respect. One author reflects, “few studies have investigated the nature, determinants or consequences of respectful treatment" (Joffe et al., 2003, p. 106). Gudzune et al. 2012 highlight the limitations of their study by noting that individual understanding of respect is nuanced, and study participants as well as coders may have had different conceptions of respect (Gudzune et al., 2012). In the Morris contribution, the research team decided on the items for inclusion in the checklist. As such, the "instrument is not a direct measure of patient preferred behaviors... some patients may be (un)comfortable with behavior the research team found respectful” (Morris, 1997). Another checklist of measures was derived from patient and caregivers’ perspectives on a lack of respect, without further conceptual clarification of the term (Koskenniemi et al., 2013).

Thirdly, another identified limitation in the research on respect is recall bias. One

qualitative study by Dickert and Kass tries to understand respect from the patient's perspective, particularly in acute care settings where patients may be unable to communicate their expectations for respectful care (Dickert & Kass, 2009). Eighteen patients participated in semi-structured interviews with question prompts on respect and disrespect in general and as respect relates to having had a cardiac arrest. Researchers identified 7 themes of respect from participant's views: attention to needs, empathy, care, autonomy, individuality, information and dignity. A finding was that female patients described respect in terms of empathy and care while male participants referred to autonomy, in keeping with "long-held views of masculine and feminine orientations to moral consideration" (Dickert & Kass, 2009). The average time since patient's cardiac arrest was 8 years, so patients were being asked to reflect on past experiences and this could introduce a recall bias. The authors conclude that their study is exploratory and that there should be further research to understand how different situations influence respectful behaviors. In this study I am developing a model of respect grounded in patients' and clinicians' descriptions of respect within clinical encounters that can further the research started by Dickert and Kass in 2009.

Summary

Within the scholarship on respect and respectful behavior, respect is often associated with patient satisfaction and quality of care. Respect may be assumed to be a right extended to all participants by virtue of their humanity or it can be more nuanced and perceived in the actions and interactions of participants. Throughout the literature, researchers concluded that there is need for further study on respect as a concept, particularly what it means to patients and this is the aim of research question 1, 'how do patients describe respect.' Likewise, some of the survey research studies have recognized that clinicians' perspectives on respect are equally important. Research question 2, 'how do clinicians describe respect' is a qualitative approach that aims to ask clinicians directly what respect means to them. In addition, there seems to be consensus that respect is an important component of patient centered care. Accordingly, we might intuit that respect is also key in shared decision making encounters. To delve deeper into whether respect facilitates shared decision making, research question 3 asks 'how do patients and clinicians relate respect to shared decision making in the clinical encounter?' and was answered by clinicians and patients in individual reflexivity sessions.

Chapter Three
Methodology

A qualitative Video-Reflexive Ethnography (VRE) study was conducted to answer three research questions: 1) '**how do patients describe 'respect' in the clinical encounter?'** 2) '**how do clinicians describe 'respect' in the clinical encounter?'** and 3) '**how do patients and clinicians relate respect to shared decision making in the encounter?'**

3.1 Setting: The Clinical Encounter in an upper Midwest Primary Care Practice

The study was carried out in the primary care internal medicine practice of a large academic health system in the Midwest of the United States. There are approximately 50 clinicians in the primary care practice whose panels may include approximately 500-600 patients who live within a 100-mile radius of the clinic.

Designing this study, I purposefully selected a slice of a patient's interaction with the health care system, the clinical encounter, as the setting for analysis. The clinical visit or encounter, understood as the time the patient and clinician meet in the room where the appointment takes place, until the time that they conclude the appointment, is a finite period where there is an interaction between the clinician and the patient. Clinical encounters included initial and follow-up visits for general medical examinations, acute and chronic care. A patient's perception of respect may have been formed prior to the time spent with their clinician and a strength of the VRE methodology is that it can

capture these past experiences. Video images are multi-layered and offer a variety of ways of interpreting the data, referred to as the 'hologrammatic' effect of VRE (Iedema et al., 2013). The moving image allows participants to bring other aspects of their healthcare experience into the discussion by reminding them of what went before and what might occur in the future.

The clinical encounter is a very private space that researchers have not always had easy access to. Researchers studying the interactions in the clinical encounter have often done so through vignettes and surveys of patients and clinicians' perceptions of the encounter (Fennell, 2005; Lutfey et al., 2008; Lutfey & Ketcham, 2005). In other instances, health service research has incorporated information from patient charts to supplement audio or video-recorded data on what occurred in the clinical encounter (Montori et al., 2011; Branda et al., 2013; Mullan et al., 2009).

Third party observations of video-recordings of the clinical encounter are another means of providing researchers with access to in-situ encounters (Montori et al., 2011; Mullan et al., 2009; Wyatt et al., 2014). Studies have included both observational reviews of video-recordings along with video-elicitation interviews (Saba et al., 2006; Neuwirth, Bellows, Jackson, & Price, 2012). Video elicitation interviews use videos as an elicitation tool to prompt participants about their recent clinical experiences without the researcher being present in the encounter (Arborelius et al., 1992; Epstein et al., 1998; Henry &

Fetters, 2012; Saba et al., 2006). VRE goes beyond video elicitation and objective video review by third parties as the researcher is present in the encounter when the video-recording occurs (Carroll & Mesman, 2011) and co-produces knowledge with participants in reflexivity sessions (Carroll, 2009; Carroll & Mesman, 2011; Collier & Wyer, 2016; Iedema & Carroll, 2010).

3.2 Video-Reflexive Ethnography (VRE)

VRE is a collaborative qualitative approach set in a theoretical frame of 'innovation from within' (Iedema et al., 2013). Participants shed light on their clinical encounters as insiders having experienced the visit themselves and as outsiders, reviewing the video-footage alongside the researcher (Carroll, 2009). Reviewing video-footage together can reveal the dynamic and complex relationship between participants in clinical encounters (Carroll, 2009; Iedema, 2009; Iedema et al., 2013). VRE was selected as participants can be observers to their own experiences and see their experience in new and different ways than if they were asked to recall a past event from memory. Seeing moving images can also trigger memories of other experiences or events that may be useful in describing respect in the clinical encounter.

The VRE methodology has been used in various studies designed to improve quality of care in clinical environments (Carroll et al., 2008). Another example of VRE improving the quality of clinical care was seen in the introduction of new information

technology for ordering laboratory tests (Forsyth, 2009; Forsyth et al., 2009). VRE was used in intensive care units (Carroll et al., 2008; Hor, 2014) where clinicians are engaged in potentially unsafe clinical practices such as handovers (Iedema, 2009). It has also been used as a teaching tool of self-reflection for clinicians (Grant & Luxford, 2009; Lammer, 2009; Leap, 2009). More recent studies have used the VRE methodology with patients (Collier, 2013; Collier & Wyer, 2016; Wyer et al., 2015).

The VRE methodology used to answer the research questions is conducted in three phases. VRE begins with a focused ethnography of initial researcher observations of the clinical setting without the camera, recruitment and video ethnography where the researcher video-records in-situ processes. The second phase incorporates ongoing analysis and data collection. The video-recordings of clinical encounters from phase 1 are analyzed and edited to be shared with participants in phase 2. Phase 3 shares results of the study with the practice to operationalize any of the suggestions/recommendations made in Phase 2.

3.2.1 Focused Ethnography

At the beginning of this study, the researcher spent more than ten hours meeting with and observing the primary care clinic. Ancillary services such as the waiting room, appointment coordinators, rooming staff and flow of the clinic were observed. These initial observations and meetings with stakeholders in Primary Care Internal Medicine,

Family Medicine and Employee and Community Health were intended to foster trust among the clinical team, prior to the introduction of the video-cameras. This period was used to explain the study and address any initial concerns. Discussions were initially held with stakeholders in the Family Medicine and Primary Care departments. While both clinics indicated support, the study benefited from a champion within primary care who facilitated the research by introducing the researcher to all staff present and by participating herself in the study and in this way, leading by example.

3.2.2 Clinician Recruitment

The Institutional Review Boards (IRB) at the Clinic and the University of Minnesota approved the recruitment of clinicians via oral consent, which is attached as Appendix I. To include shared decision making encounters in the qualitative sample, clinicians were purposefully recruited, prior to the appointment, from a list of those clinicians who have previously or are presently using decision aids for chronic conditions such as diabetes, statin choice and depression. The Knowledge and Evaluation Research (KER) Unit at the clinic where this research originated, was recruiting clinicians and patients to participate in a separate study using a range of decision aids. Study coordinators within the KER Unit identified primary care clinicians who were familiar with the diabetes, statin choice and depression decision aids as potential study subjects for this study. Twenty primary care clinicians, nurses and physicians, who had prior

experience with decision aids were identified and contacted in person or by email informing them about the study. Those who expressed interest were met in person to discuss the logistics of the study and were consented in their offices. After recruitment, clinicians were asked to recommend other clinicians who might be interested. In this way, additional clinicians were recruited through referral sampling of primary care clinicians within the health system.

Although clinicians eligible for inclusion initially included physicians and nurses, the one nurse in the sample who replied to initial emails declined to participate based on a re-assignment to another clinic and an increase in her administrative workload. The resultant sample of clinicians was physicians from primary care internal medicine. Consultants from primary care were recruited as leadership felt that residents are still learning and it would be unfair to video-record them and have them reflect on their encounters (outside of a training exercise).

Many of the clinicians who consented to the study had been practicing in the primary care clinic for many years and were not taking new patients. However, during the initial video ethnography sessions I found that respect in the clinical encounter often revolved around whether patients and clinicians had an established relationship. Therefore, I felt it was important to include participants who did not have an established relationship. I purposely recruited clinicians who were younger and newer on staff. I

considered recruiting fewer clinicians and more than one patient per clinician to get a better sense of the effect clinicians have on patients' perceptions of respect. However, I believed that it was important to get as many perspectives as possible and decided to recruit an equal number of clinicians and patients. The final sample consists of 17 primary care clinicians.

3.2.3 Patient recruitment

Once clinicians consented to participate in the study, they were asked to identify patients with a chronic condition who had an appointment in the upcoming weeks and who they felt would be able to participate in a follow-up video-reflexivity study. The criteria for selection was over 18, speaks English, has a chronic condition and would be willing to participate in a follow-up reflexivity session. In identifying patients, clinicians were cognizant of patients' ability to return for the follow-up visit (distance from hospital, needed to be accompanied, mobility and cognitive issues for example were considered). Clinicians identified one to four potential patients who might be eligible to participate. I started with the first scheduled patient for each clinician and stopped recruitment after the first patient agreed to participate. From previous experience, the study coordinators at the clinic recommended recruiting patients on site, prior to their appointments. There may be less emphasis placed on 'performing for the camera' if patients have less time to consider the implications of themselves being video-recorded.

Patients were invited to participate in the study in their clinical room, after they had been seen by nursing staff for their scheduled appointment and prior to their clinician entering. During the initial recruitment period, patients were asked to participate in a study about patient centered care. Recruitment was modified to mention respect explicitly for the participants in later encounters. Participants were asked to consent to having their clinical encounter video recorded and if acceptable, for an observer (myself) to be present during the clinical encounter. It was made clear that the researcher could be asked to leave the room or cover, switch off or aim the camera toward the wall at any time. The researcher left the room and turned cameras off/down during the physical exams. Patients could withdraw from the study at any time and did not need to answer any questions that they did not want to. In addition, the consent process made clear that patient information would be treated confidentially and that their care would not be tied to them engaging in the research. While the researcher took notes, it was emphasized that no protected health information would be recorded in the field-notes. The recruitment guide that was used to recruit prospective patients is Appendix II.

Very few patients declined to be in the study, of the 19 asked to participate 4 (21%) declined. One person who declined was older than 91 years of age and limited by their ability to independently return to the clinic for the video-reflexivity study. The second and third patients held personal grievances with the clinic and health care in

general and declined participation. The fourth patient who declined did not provide a reason and I did not pursue recruitment any further. The final sample includes 15 adult patients with a chronic condition and 4 caregivers who accompanied patients to their clinical encounters.

3.2.4 Video Ethnography

Video ethnography uses video technology to observe and capture real-time in situ-care. Carroll (2009) posits that there are two ways of engaging in focused video-graphic ethnography. One where the researcher is naïve to the process and films as a 'fly on the wall' and captures the behaviors and processes of the clinical encounter unobtrusively. Second, the 'expert-apprentice' style is where the researcher is an apprentice to the participants and they direct the video-recording by narrating their practice style to the researcher or directly to the camera (Carroll, 2009). For example, a study with patients as the experts gave cameras to patient participants and asked them to video-record experiences that were important to them (Collier & Wyer, 2016). Filming involves choices on what is filmed, the frame used and where the researcher is positioned during the filming (Carroll & Mesman 2011; Iedema et al., 2013). This study utilized the fly on the wall style of video-recording clinical encounters and as the researcher I tried to

be as unobtrusive as possible so that the limited time that participants have in their clinical encounters would not be disrupted by the study.

Fifteen clinical encounters were video-recorded with two small cameras mounted on tripods. The encounter was video-recorded with a Go-Pro camera with a second camera, Flip or Go-Pro used as a back-up resource in the event of any technical failures and to capture the encounter from different viewpoints. Cameras closer to the clinician put the emphasis on the clinician when reviewed and cameras with a wider angle of the room offer a broader perspective of the encounter and placed the patient at the forefront of the video-footage that would be reviewed in the subsequent reflexivity sessions.

Analysis of clinical encounter video-graphic data

The videos were uploaded from the cameras immediately after the video-ethnography and were stored on a secure server. Ethnographic knowledge gained in phase 1 is used by the researcher to edit video-footage, differentiating VRE from other video based methods (Carroll & Mesman, 2011; Collier, Sorensen & Iedema, 2015). Previous VRE studies have shown that clips from 2-10 minutes are sufficient to elicit discussion from participants. For example, Carroll created a DVD of 15 minutes with footage from two ward rounds for a reflexivity session with ICU clinicians; and a team in the Netherlands who filmed post-operative handovers stated that video-clips in reflexivity

sessions should not be more than 2-4 minutes in length (Iedema et al., 2013). The 45 minute to one-hour video-recordings of the clinical encounters in this study were reviewed and edited by the researcher into on average six clips of 2-5 minutes in length for the reflexivity sessions. The edited clips included the beginning of the encounter, introductions and history taking, the treatment decisions and the end of the encounter. Additional clips varied by reflexivity session depending on unique aspects of the clinical encounter observed by the researcher.

3.2.5 Video Reflexivity

Participants in this study were invited to participate individually in a video-reflexive activity where they reviewed an edited video recording of their clinical encounter, and as an observer to the encounter reflected on their experience. Participants were re-consented on the day of their reflexivity sessions, to gain consent to further video-record the reflexivity sessions. Ongoing consent has been sought to use clips from the video-reflexivity study for future research and presentation purposes. Consideration was given to asking participants to jointly review the encounter in a team based group reflexivity session. However, given the underlying hierarchy between patients and clinicians (even in a shared decision making, patient centered environment) this idea was not pursued as I did not want to subject any participant to an environment where they

would feel unsafe or uncomfortable. This may especially be the case for participants who see each other on an ongoing basis to address care for chronic conditions.

Participants were invited to meet in a small conference room at the Clinic, or at a mutually agreed upon convenient and private location (e.g. the clinician's office, the library/conference room in the primary care clinic, or at a patient's home) to review the video recording. Participants' views on patient centered care in general and respect specifically were elicited while reviewing video-recordings of their clinical encounters. To answer research question 3 (the connection between shared decision making and respect), participants were also specifically asked if a decision was made, how the decision was made, who participated and who ultimately made the decision?

Interview guides in Appendix III were used to prompt discussion prior to watching the video-graphic data and as prompts during the discussion of the videos. Interview guides were modified depending on the nature of the clinical encounter and as the analysis was performed iteratively with the video-reflexivity sessions. For example, numerous participants highlighted the importance of "feeling comfortable" and future participants were asked to help the researcher understand what this meant to them. This concept was not included in the original interview guide. Changes were also made to share with participants what the other member of the clinical dyad had mentioned in their reflexivity session. For example, clinicians were told what patients thought at a particular

moment in the recording, especially when it differed from clinicians' initial impressions. Conducting the analysis iteratively is different to a quantitative approach where the emphasis is on consistency in questions posed over time and among participants. Strauss and Corbin (1990) caution that this does not mean that there is no standardization of data collection. Initial questions will remain in the interview guide (unless deemed irrelevant); and any concepts garnered from an initial analysis of the data should be incorporated into further questions and interviews (Strauss, 1990). Sequential data collection plus systematic analysis "allows the expansion of the research process to capture all potentially relevant aspects as they are perceived" (Strauss, 1990). Interview guides were also modified when individual events or behaviors stood out to the researcher. When events played for participants did not elicit further discussion on review, probes were used to invite participants to explore that subject more deeply. For example, I probed into what is the significance of setting up the next appointment or 'planning for the future'. Additional prompting was also necessary when a video-clip contained more than one topic for further discussion. Participants reflected on one of the topics and not the other, usually the topic most recently viewed but when reminded would also comment on other issues contained in the video-recording.

3.3 Analysis – Grounded Theory

Grounded theory originates in sociology, particularly the notion that "meaning is negotiated and understood through interactions with others in social processes" (Starks & Brown Trinidad, 2007). A grounded theory approach intends to generate or discover a theory (Creswell, 2007) from a process that all the participants have experienced. The methodology stresses that the theory is derived, 'grounded', in data from the participants themselves. According to Strauss and Corbin (1998), grounded theory "is a qualitative research design in which the inquirer generates a general explanation (theory) of a process, action or interaction shaped by the views of participants" (Creswell, 2007).

Charmaz highlights eight elements of grounded theory to guide researchers using this methodology (Charmaz, 2014):

- Data collection and analysis simultaneously
- Analyze actions and processes
- Use comparative methods
- Draw on data for conceptual categories
- Develop inductive analytical categories
- Emphasize theory construction
- Engage in theoretical sampling
- Search for variation

The elements include the interplay of data and theory such that the first set of data collection and analysis occur iteratively. Data collection from video-recordings of shared decision making clinical encounters and from the reflexivity sessions provided additional

data to be analyzed. Following the grounded theory methodology, each interview was analyzed prior to the following interview so that emerging themes could be incorporated in an iterative process. The data was transcribed (by the researcher and a trained medical transcriptionist). Personally transcribing the video-recordings is another way of getting embedded into the data and though this is a lengthy and tedious process, deepens the researcher's knowledge of the context of the data. Given the quantity of data gathered, it became a practical solution to seek assistance with transcription of later video-reflexivity sessions to move the rest of the study forward. The data was iteratively analyzed per a social constructionist approach to grounded theory where data is co-constructed by the researcher and participants (Charmaz, 1990). This research follows the constructivist grounded theory per Charmaz (2006) where the researcher, the research and the emergent themes are interconnected. As such, the conditions under which respect may occur and the consequences of actions deemed respectful were co-constructed between researcher and participants in reflexivity sessions and data analysis. Reflecting on my research biases, I envisaged respect to be described by both behavioral and attitudinal characteristics that may be observed during the encounter. I imagined that participants would highlight introductions, eye contact, attentiveness, tone, listening, disruptions and communication as characteristics of respect and that these verbal and non-verbal cues would lead to more in-depth instances of respect. I was prepared to prompt participants to

address these issues if they were not raised while remaining open to participants having completely independent ideas of what respect meant to them in their unique clinical experience.

The video data from the initial encounters plus the video-reflexivity study were watched repeatedly and the transcripts read in their entirety 2-4 times to obtain a familiarity with the clinical encounter and the video-reflexive discussions. Memos were made of major ideas that emerged from both participants and the researcher during this initial review process. The researcher also used memo-writing to record emotions that may affect the analysis and justifications for why certain research decisions were made (Charmaz, 2014). For example,

> 4/19/2015 *"The video was 41.30 minutes and given the one-hour allocated for the video-reflexivity session it needed to be edited, or select parts chosen for review with the patient participant. Dr. Carroll has advised that what I thought was not useful and should be edited may actually be where respect was shown. After watching and listening to the encounter (particularly scenarios that stood out for me) I decided to use 4 segments (1) the introductions and initial discussion of the clinician presentations (0.00-5.15mins) (2) addressing the patient's concerns (29.28-33.05 mins) (3) the treatment plan (34.50-38.00) and (4) additional concerns and farewell (38.05-41.30). I also read the Wyer et al. 2015 paper and thought that it'd be interesting to show some segments of the video with and without sound. Missing from the edited segments is one at 13.58 where the clinician makes a strange sound that startles the patient (would be a good moment to reflect on if time permits)"*

Another element recommended by Charmaz is the use of comparative methods (Charmaz, 2014). Constant comparisons of the data are made to identify like concepts. Initial codes and memos are made to ensure that what the researcher thought was a like

concept fits with new data as it is collected. In this study, transcriptions were initially line-by-line coded using gerunds to stay as close to the context of the data as possible. Using action words allowed the data to stay active and fluid and retain the perspective of participants. "The initial grounded theory coding with gerunds, is a heuristic device to bring the researcher into the data, interact with them, and study each fragment of them" (Charmaz, 2014).

Next, the researcher must ask theoretically oriented questions to go beyond initial descriptions of the data. This leads to focused coding which identifies relationships among concepts and categories to reveal patterns among participant perspectives (Charmaz, 2014). The next stage of coding was theoretical, to develop an analytical description of the characteristics of respect described by participants in clinical encounters. Initially many themes emerged that were theoretically subsumed in broader themes during the analysis. For example, question 2 originally included the following themes frame/boundaries/space, being strategic and doctor role which were later included in a broader theme of institutional boundaries and finally as 'respect as work'.

Previous studies using VRE methods vary on how the video-graphic data was analyzed. Hor et al. (2014) report that they used grounded theory to analyze semi-structured interviews and observations and that these findings informed a second phase of the research which involved video-ethnography and reflexivity. The findings of this

second phase are reported in a descriptive manner and it is assumed that they emerged from analysis of the video-graphic data (Hor, 2014). Collier and Wyer display their VRE studies in a table and analysis occurs throughout the study and begins with an analysis by the researcher of what participants identified as pertinent issues in a descriptive manner (Collier & Wyer, 2016). In another paper Collier outlines how she began the process of analysis by generating themes from the transcripts of reflexivity sessions but that further analysis of these themes was refined through participant analysis of these initial themes that was also video-recorded, and participant meaning and understanding of the initial theme was evidenced in response to them watching clips of the initial themes. The researcher then modified the initial themes based on participant input (Collier, Sorensen & Iedema, 2015; Collier, Phillips & Iedema, 2015). Iedema describes analysis in terms of 'structured analysis' and 'footage analysis'. In this way video-footage is analyzed according to themes ascribed by the clinical teams prior to the start of the study. Once video-clips are organized according to this original top-down analysis, participants are able to add a further layer of analysis during reflexivity sessions. Video-recordings of the reflexivity sessions are analyzed through 'formal video analysis' of the pre-existing themes (Iedema, 2012) and Carroll et al. note that video-graphic data from reflexivity sessions was coded and three themes emerged in a study on ICU ward practices (Carroll et al., 2008). Descriptions of analysis in VRE studies demonstrates that analysis is an

ongoing process and begins during the video ethnography where initial themes emerge that guide the editing of clips for the reflexivity sessions. Transcripts of the video-reflexivity sessions are then either coded per grounded theory with various levels of coding and the emergence of themes or through a structured content analysis with pre-existing themes. The research questions in this study were answered using grounded theory so that participant perspectives could shape the emergent description of respect and inform how respect in the clinical encounter is related to shared decision making.

3.4 Data Storage

Patient and clinician observations were recorded without names or other patient identifiers. Recordings of clinical encounters and reflexivity sessions have been saved on a secure server, with access given only to those on the IRB approved study protocol. Video- recordings of clinical encounters were stored with numeric identifiers. Given that the data comprises video-recordings, although no identifiers were attached to the recordings, participants' facial identifiers were stored. Transcripts are housed in secure folders on a password-protected computer, which can be accessed by a select number of study personnel with IRB approval for this study. Additional field notes are stored in locked filing cabinets and on password protected servers.

3.5 Practice Optimization

The third phase of VRE, practice optimization, sharing insights with practice will occur at the end of data collection and analysis of all three research questions. It is not part of this dissertation. However, in the future, discussion and feedback from the reflexivity session with practice stakeholders could also inform the emergent descriptions of respect and how respect is related to shared decision making in the clinical encounter so that these can be implemented in practice.

3.6 Ethical Considerations

IRB approval for this study has been granted by the clinic's IRB, and from the University of Minnesota IRB.

3.7 Member Checking, Credibility and Transferability

Member checking: Throughout the data collection and analysis process, two patient advisory groups were asked to comment on the credibility of initial researcher interpretations of participant views on respect and what was missing. Two committee members also engaged in a 4-hour analytic review of the data analysis and emergent themes as a form of member checking the analysis. Moreover, and following the

procedures of grounded theory I relied on discussions with colleagues to test concepts and theories under development.

The call for a new way of describing humanistic qualitative research has received prominence recently (Cheshire, 2016; Lather & St. Pierre, 2013). Cheshire emphasizes the tension between qualitative inquiry and the scientific structural concepts that frame qualitative research (Cheshire, 2016). The question is discussed as to how qualitative researchers can ensure that the rigor of the research is demonstrated without using quantitative, positivist terminology? The author concludes by demonstrating qualitative rigor with such criteria as: credibility, the trustworthiness and plausibility of the research findings (Cheshire, 2016). Charmaz also lists credibility among her criteria for evaluating a grounded theory study (Charmaz, 2014). To this criterion I have added transferability.

Credibility: To establish trustworthiness of the data or credibility, I engaged directly with participants in situ where their clinical encounters took place. The credibility of the data was derived from verbatim transcriptions of video-recordings of the encounters. The closeness of the researcher to participants in the field contributed to the accuracy of the data in the study. Moreover, the degree of time spent in the clinic and with individual participants was akin to Pink and Morgan's description of a focused ethnography

'characterized by forms of intensity that lead to deep and valid ways of knowing' (Pink & Morgan, 2013). The authors go on to reflect that during the analysis phase of a VRE study, there is continued 'depth and immersion' in the data (Pink & Morgan, 2013). Throughout the study, I continuously engaged in personal reflexivity to document how I believed I influenced the co-creation of data and to reveal research biases and assumptions. Finally, the results are substantiated with examples of text from the data and where possible video-recordings themselves to demonstrate that the emerging description is an accurate portrayal of participant's perspectives.

Transferability: According to Strauss and Corbin (1990), the more abstract the concepts, the more applicable they are. Once the conditions under which respect occurs are specified, then others (practitioners, health systems, policymakers) may apply the theory in similar situations (Strauss, 1990). To ensure the transferability of the methodology used, detailed descriptions of the video-reflexivity method and grounded theory analysis are provided, particularly the contextual factors such as location and participants as well as the conditions under which certain concepts were observed. The results of this study will be transferable to other health systems that share similar conditions as those of the primary care internal medicine clinical settings in this study.

3.8 Positionality: The researcher and the research

In qualitative studies, researchers are often aware that their experiences, views, beliefs and attitudes cannot be separated from the research (Charmaz, 2014; Cheshire, 2016; Lather & St. Pierre, 2013). As such, researchers engage in their own reflexive processes to constantly be aware of their reach into the research (Carroll & Mesman 2011; Collier & Wyer, 2016). In the interests of transparency, I reveal to the reader my life experiences, beliefs and attitudes toward respect so that the readers may judge for themselves how these may influence the research study. My approach to most social and political contexts is grounded in my early childhood experiences growing up on a small island that is easily described as a low to middle-income developing country. First-world luxuries remain a wonder, none more so than in the area of healthcare. I am a social democrat who believes in the universal right to healthcare and I embrace the notion that health is a basic human right. My early career was centered in the world of diplomacy and development and I continue to subscribe to the philosophy that we should do whatever we can for those around us to achieve their highest potential. I am also a daughter, mother and wife, to whom family is fundamental. The research is being undertaken in the context of managing these competing demands and this is being shared for no other reason than to let the reader know that the research study is one of a plethora of activities that I am engaged in.

As part of positioning myself as researcher in the study, I continuously engaged in researcher reflexivity and memoing. Being privy to others' clinical encounters was cause for much personal reflection. Over time my familiarity with primary care and the relationship between patients and clinicians has been awe-inspiring. The depth of the relationship and its influence on the care received undoubtedly frames the context within which respect emerged in the encounter. I was reminded on numerous occasions how intimate the relationship between patients and clinicians is when patients cried and used such language as 'devastating' to describe the loss of a clinician; how deep the relationship is when one elderly patient lamented that her physical limitations prevented her from 'seeing her two best friends' who she visited with twice a week for over 50 years and in the same conversation described her clinician 'like my best friend'. It was especially uncomfortable for me to be in the room when such personal conversations as a participant's sexual functioning was discussed at length, when a participant underwent cognitive testing for dementia for the first time and when a participant declined to participate because they did not want me to record or witness the discussion of their history with their clinician which included a long journey and many canceled appointments. I realized how privileged I am to be a part of their healthcare experience, to be able to share, record and revisit with them these intimate moments and it highlighted for me as researcher how important respect is to the research as well and how

respectful VRE is as a methodology as it gives the participants control over when recording occurs and what is recorded.

While I undeniably affected the generation and interpretation of the data in this study, it should also be noted that in a VRE study the researcher and participants develop novel data by engaging with each other. The reader also has a unique way of interpreting the results of the study, which may differ from the researcher, and which should also be taken into account.

3.9 Summary

This research is a qualitative VRE study. VRE was used to generate a description of the characteristics of respect in the clinical encounter according to patients and clinicians. This is a novel approach, as the use of Video-Reflexive Ethnography is relatively new in the United States and there is a dearth of literature on a description of respect grounded in participants' perspectives. Involving patients directly in VRE studies is also relatively new (Collier & Wyer, 2016) and is in keeping with calls for greater collaboration with patients on patient centered research. A further analysis was done to see whether the descriptions of respect are related to shared decision making in the encounter. The results of this analysis may inform policymakers of the characteristics of respect described by participants in the encounter themselves, that are impacting the quality of shared decision making healthcare delivery.

Chapter Four
Results

The data described in this results chapter emerged from twenty-seven individual one-hour video-reflexivity sessions with fourteen clinicians, thirteen patients and three caregivers. Three of the video-reflexivity sessions were conducted with both the patient and their caregiver, both of whom had also participated in the clinical encounter together. I drew on participants' own words describing what respect means to them. The various participant descriptions of respect were qualitatively analyzed and resulted in four analytical descriptions of respect: valuing individuality, valuing agency, valuing feeling comfortable, and valuing partnership. The results are presented according to the three research questions:

Research Question 1: How do patients describe respect in the clinical encounter?

Research Question 2: How do clinicians describe respect in the clinical encounter?

Research Question 3: How is respect related to shared decision making?

4.1 Question 1: How do patients describe respect in the clinical encounter?

The data used to answer research question 1 emerged from thirteen one-hour video-reflexivity sessions with thirteen patients and three caregivers. As shown on Table 4, patients were on average in their late sixties, mostly female, white, married and educated. During the reflexivity sessions, edited video-recordings of the clinical

encounters were shown back to patients. Four caregivers accompanied four patients to their encounters and were active participants in the encounters, sharing in decisions and treatment planning. One of the spousal caregivers did not accompany her husband during the reflexivity session. The encounters themselves were equally split between general medical exams and follow-up appointments for chronic care. Conditions addressed in the encounters included patients' chronic conditions such as asthma, osteoporosis, depression, hypertension, heart failure and other cardiac diseases, diabetes and obesity. Patients raised additional concerns such as leg pain, medication dosages, memory loss and lifestyle. The osteoporosis and statin choice decision aids were used during four encounters.

Table 4: Characteristics of the Clinical Encounter, Reflexivity Sessions and Patients

Encounter characteristics	**Encounters (n=15)**	**Patient Characteristics**	**Patients (n=15)**
General Medical exam Follow-up	50% 50%	Gender: Female Male	80% 20%
Length (Average)	39 minutes	Age (Average)	69 years
Decision aid used	27%	Race: White African-American Native American/Hawaiian	80% 7% 13%
Caregivers present	27%	Status: Married Single Divorced	80% 13% 7%
Length of reflexivity sessions (Average)	58 minutes	Education: Post-graduate Some college High school	33% 42% 25%

Identifying Themes

In the first four (27% of total) reflexivity sessions I began with open-ended questions about patient centered care. In the next ten reflexivity sessions, the concept of respect was introduced immediately, to be able to better understand whether what patients were describing about their encounter reflected their understanding of respect. Participants were asked to review 4-6 edited video-recordings of their clinical encounters, each approximately 2-4 minutes in length, focusing on the introductions, history taking, treatment planning and end of the encounter in all the reflexivity sessions. In the final 6 reflexivity sessions, patients were asked to review 1-2 edited video-recordings of the history taking, treatment planning or end of the encounter as well as 2-4 edited video-recordings of the decision making in the encounter. Data for research question 1 emerged from the discussions around the communication in the encounter and not the decision making. While some participants were familiar with the concept of respect, others initially struggled with how they would describe it. After participants commented on the video-recordings, the researcher used prompts and further questioning to engage participants in discussion around topics or concepts that the researcher had observed in the encounter and after seeing the videos. The discussion on respect and the clinical

encounter was video-recorded and transcribed verbatim. Following the principles of grounded theory, the data was co-constructed and analyzed simultaneously, allowing for interview guides to be revised as new categories emerged. The entire transcript of the reflexivity session was coded according to the following steps:

(1)Initial coding – data was line by line coded using active words (sometimes the participant's own words) to code what was discussed during the reflexivity sessions. Line by line coding adds 'a label that simultaneously categorizes, summarizes and accounts for each piece of data' with the aim of making an 'interpretive rendering' of participants' reflections (Charmaz, 2014). An example of initial coding is given in Table 5 where Margaret, a relatively healthy 61-year old patient with hypertension, was reflecting on her clinical encounter with her clinician, whom she had met for the first time in that encounter. Margaret remembered how she felt in the appointment and what strategies she employed to manage the interaction. From Margaret's own words, I line-by-line coded and analyzed what she had said and then later refined those codes into more succinct initial codes which informed further focused codes.

Table 5: Examples of line by line coding

Initial Narrative to be Coded	Examples of line by line codes
Researcher: To start, when you think back to that appointment, I know that it was the first time that you met Dr. (intentional omission), can you walk me through it? Margaret: I was basically very comfortable, I felt that he listened you know to what I had to say, especially considering that he was walking in cold and I don't think that they get a whole lot of prep time as far as meeting or reading or looking over charts from new patients, you know, but he listened to my concerns and we are investigating a couple of things and that's ok, (laughter) ok. I wanted to find out you know testing, I don't think it'll be so great but it's a pulmonary function test and also the stress test… *Researcher: I noticed that you went in with notes, do you normally do that?* Margaret: a lot of times, just to jog my memory just as far as things that I really want to talk about, you know, especially with someone for the first time, normally Dr. xxx and I would have built off the last appointment	Feeling comfortable because clinician listened; not expecting clinician to know much about a new patient; understanding challenges of a new encounter; listening; expressing satisfaction with treatment plan Wanting answers; thinking negatively about treatment tests Using notes as a strategy; prioritizing the patient agenda; realizing challenges of first encounter; continuity facilitating process

(2) Focused coding – In Kathy Charmaz's constructivist grounded theory, focused coding is 'interacting with and acting upon your data' (Charmaz, 2014). By studying and

comparing various initial codes, I chose focused codes that I felt subsumed other codes and were most useful in capturing the intent of patient's descriptions of respect. These codes appeared more frequently within initial codes or seemed to have a special significance for patients. In Table 6, we can see how patients described the patient as person, recognizing the person, prioritizing patient's concerns and sharing personal information and how during focused coding these descriptions were coded as seeing the patient as a person.

Table 6: Example of focused coding

Excerpt 2: George describing how his clinician respects him	**Line by line codes**	**Initial code**	**Focused code**
George: I expect respect and recognition and wanting to listen. His willingness to listen to concerns that the person, that you have. Well part of the respect is the listening, hearing what I've got to say vs. whatever his agenda might be. *Researcher: How do you think he shows recognition, or how does he recognize you as who you are?* George: Well, I think he starts asking out by asking what my concerns are, you know, and what other specific concerns, aches, complaints.	Recognizing the person Wanting to listen to patient's concerns Describing the patient as person Prioritizing patient's agenda over clinician's Discovering the patient and the patient's concerns Sharing technical,	Seeing the patient as person Prioritizing Introducing personal aspects	Personal, social context Contributing to care Personal, social context

Excerpt 2: George describing how his clinician respects him	**Line by line codes**	**Initial code**	**Focused code**
Researcher: So do you like his practice style? George: Yes, because he's giving the technical but also giving clarification. George's wife Helen: I think the other thing is he talked about some personal things too.	medical information with explanations and personal information	Sharing personal aspects	Personal, social context

Researcher memos also contributed to the focused codes that are described in Table 7 that coalesced around, seeing the patient as person in a broader social context, behaviors that were exhibited, extra attention that was shown to patients, contributing to care and validating and adapting care to meet patients' concerns as well as personal, clinician and environmental affect. Further analysis of the data resulted in analytical themes framing participant's descriptions of respect as of value, valuing individuality, agency and feeling comfortable.

Table 7: Coding schema

Initial codes	Focused codes	Analytical themes
Patient as important, interesting, individuals Introducing personal aspects into the dialogue Sharing personal stories, perspectives Clinician as person	Personal, social context	Valuing individuality

Table 7: Coding schema

Initial codes	Focused codes	Analytical themes
Listening Communication style Flexibility/compromise Personalized care	Behaviors	
Time Going above and beyond	Extra attention	
Agenda setting, prioritizing Patient's needs are expressed Sharing responsibility for care Working together	Contributing to care	Valuing agency
Patient's concerns are validated Validating involves responding to and answering concerns Validating clinicians	Validating behaviors	
Expressing Emotions Feeling at ease, not threatened Being open, ability to open-up	Personal affect	Valuing Feeling Comfortable
Caring Being non-judgmental Being a Friend	Clinician affect	
Valuing an in-person dynamic Developing Rapport Understanding the role of humor Affecting comfort levels via verbal and non-verbal cues	Environmental affect	

4.1.2 Valuing individuality - Seeing the patient and provider as person

For ease of reference, Table 7 has been divided according to the three analytical themes. Each theme is discussed separately in the results section and Table 8 lays out the initial and focused codes that resulted in the 'valuing individuality' theme.

Table 8: Codes that formed 'valuing individuality' theme

Initial codes	Focused codes	Analytical themes
Patient as important, interesting, individuals Introducing personal aspects into the dialogue Sharing personal stories, perspectives Clinician as person	Personal, social context	Valuing individuality
Listening Communication style Flexibility/compromise Personalized care	Behaviors	
Time Going above and beyond	Extra attention	

Most patients (approximately 75%) described respect as seeing the patient in a broader personal and social context which they felt was shown by patients sharing personal stories, and clinicians understanding the patient and prioritizing their concerns. I describe these as components of respect that emphasize valuing individuality. Valuing the individuality of the patient was also shown when clinicians exhibited certain behaviors such as listening, compromising and personalizing their care and when clinicians paid them extra attention, not only as patients but as persons outside of the patient role, both within the encounter by spending extra time with them and outside the encounter with follow-up calls.

After watching segments of their encounters, patients often described interactions that made them feel that the clinician saw them as a person, within their broader social context. Helen, the spouse of George who was in the clinical encounter and participated

in the follow-up reflexivity session described her thinking on knowing the patient in their broader context when their clinician:

> "*knows me outside of the office and turns up things about family and other issues. Looking at me in decision making able to point out this has worked, this hasn't. Respect comes in the listening and decision making together"*.

In Julie's case, she felt that she needed to share with her clinician her broader personal story that her husband had been diagnosed with Parkinson's, as this would ultimately affect her own health, "*I wanted to tell her that because that's more stressful for me and that's going to affect my health and I think the doctor should be aware of it*". Sharing personal stories with his clinician that his brother had passed away and that his grandson was sick encouraged Humphrey to reflect that his clinician is interested, "*not only about me but everyone else*." Sharing her personal context with her clinician resulted in Margaret's clinician understanding her broader context and health care philosophies, "*I did feel like my questions got answered and you know that he understood why I was asking some of them too"*.

Not only did patients describe respect as valuing the individuality of the patient, they also noted that it was important for patients to see their clinicians as persons, as individuals, in a broader context. Storytelling is one way of reducing the hierarchical structure of the encounter, and patients felt that clinicians showed them respect by also sharing some of their personal stories. Patients, such as Oliver felt that it was beneficial

for clinicians to share some of their stories and experiences, "*I would have to say that, over the years, he will share personal information that he's experienced the same things that I've experienced. I felt that was respectful of me."* Rachel evidenced her clinician's caring attitude by the fact that "*we've even talked about, she even told me about her vacation."* Lily lamented that during the physical examination she had shared her story with her clinician but "*I had wanted to ask him a little bit about him too, but I didn't get that done. So I'll have to do that next time."*

In one reflexivity session, a patient described a clinician's behavior as disrespectful. It was unclear whether this was the case or whether respect in the encounter was affected by the patient *not* getting to know the clinician as an individual. Humphrey digressed from his appreciation of his current clinician to discuss a primary care clinician that his wife previously had, "*she had a different doctor at the Baldwin building, he was a guy and she didn't like him, he was from India or something."*

Mutual respect was another way that patients described respect for their clinicians in the encounter. Jean struggled with defining respect but likened it to mutual feelings for each other, "*if I like somebody, I like them because I respect them, and they like and respect me*". Lily believed that the way she participated in the encounter when her clinician was entering orders was something "*that we could do together, you know, kind of a mutual bonding. I think it was a mutual respect for each other."* Humphrey noted, "*I*

just have mutual respect I guess for the doctors." Ana felt similarly and described the consequences of not respecting your clinician, "*as far as the doctor is concerned, if you don't respect him, you're not going to respect what he says is wrong with you. So you're not going to necessarily follow through with what's going on."*

Patients felt that it was not only what clinicians said but how clinicians behaved that reflected respect. This was true for Rachel who said about her clinician, "*she's actually made me feel like the patient is the most important thing."* Sonia's husband also described behaviors that suggest that Sonia's clinician is interested in her as a person, "*Well, Dr. X always seems interested and focused on Sonia*". When George was describing his expectations for the visit he included "*Respect and recognition and wanting to listen*". When he expanded on what respect means to him, he described it as "*listening, hearing what I've got to say.*" Patients also felt valued as individuals when clinicians appeared to be more flexible about their care. For example, Humphrey described his clinician's willingness to compromise on her recommendations that he take his new diabetic medications at nighttime, when she understood his personal reasons for preferring to take his new medication with all his other medications in the morning, "*I thought that she compromised for what I wanted her to do.*" Another example of personalizing care to that specific patient was given by George who described the care

that he experienced as respectful when the clinician remembered him as a person whose body was unique:

> "*I think that the way he personalizes and that he remembers who you are. For example, when he does the prostate exam, he remembered the way my body is structured he has trouble feeling the prostate… it was his acknowledgement."*

Patients also described numerous ways in which they felt their clinicians demonstrated respect for them specifically as individuals by giving them extra attention, either by spending time in the encounter with them so that they felt more than 'just a number' or by actions that are above and beyond what is expected of the clinician, Humphrey noted "*I like that extra tender care that she gives you*".

Institutional factors outside of the clinician and patient's control also influenced how respect was perceived in the encounter. The length of time allocated to each encounter is usually set by an institution and clearly affects the perception of respect. Time was central to patients' descriptions of whether they felt that the doctor had treated them as an individual and in patients' own words, they were impressed when clinicians made the time in a limited 30-minute encounter to discuss non-biomedical issues. The clinician taking the time to get to know patients was clearly important to Margaret, who was surprised that in a general exam where they could have spoken mostly about tests, that her new clinician took the time getting to know her. For Margaret, this was respectful because her clinician prioritized getting to know her within the set time limits of the

appointment over pursuing his medical agenda, "*I think that he took a lot of time with me. And you know that's also respectful."* Taking 'extra time' was also described as respectful by Rachel and she believed it contributed to continuity of care:

> "*Respect goes a long way. They need to have extra time with their patients. That's part of the respect. If they feel like they're just nothing more than a number and paycheck to them, they ain't gonna wanna come back."*

In addition to 'taking the time', patients observed clinician behaviors that suggested that their clinician was willing to do something extra just for them, such as giving the patient something. In one case, the clinician gave her personal book on managing diabetes to her patient Humphrey. Humphrey, a native Hawaiian who was meeting with his clinician specifically to discuss his new diabetes diagnosis, was struck by how the clinician doing something extra for the patient demonstrates respect in the encounter, "*and then she leant me her personal book to read ya know, so that was good; so you know that she cares about you because she wants you to do good. So she took time to go out find a book and bring it back."* Sonia also described her clinician doing something extra for her as respectful. After viewing the final edited clip of the encounter where her clinician goes outside of the room to bring in her wheelchair, Sonia linked respect with the clinician going the extra mile by 'helping' her, "*If I didn't feel they respected me, I wouldn't feel they were going to help me, right?"* Moreover, Sonia's husband shared an anecdote of her clinician's willingness to do things specifically for

her, even if it meant driving her car herself to take Sonia to appointments that she was missing. Sonia's clinician had said, "*now I'm going to give you my private number, and if she doesn't want to show up for this, I'll jump in my car and I'll come and get her"* leading her husband to remark, "*that's the kind of outreach she gives you, which is amazing."* Another 'extra' behavior outside of the encounter that Margaret found particularly respectful is the clinician practice of making follow up calls:

> *Researcher: if you see anything that you think is particularly respectful in terms of behavior just point them out to me.*
>
> *Margaret: well I think the fact that he was going to personally follow-up you know with the tests that I was having.*

Like Margaret, Ana also felt that caring enough to make follow-up calls was respectful.

> *Researcher: What does follow through mean to you in terms of respect?*
> *Ana: Well, I think for a doctor to follow up simply means that they care enough to check to see what they recommended worked or that, you know, that you are at least following the guidelines that I've given you. I think it shows a sense of caring... I think that sense of caring shows that, you know, you respected me enough to 1) validate my concerns and 2) you know, you addressed, supposedly, my needs. So I think, definitely, it's a sense of respect, yeah.*

Indeed, Ana had earlier shared that her clinician not following up on her visit to the clinic when she saw another member of the care team was interpreted as disinterest in her as a person and led to the perception that respect was lacking:

> "*I guess that sends a message, when you can't ever get to your doctor or when the doctor doesn't call you and say, you know, I noticed you were here for the last two visits and I wasn't around, I just wanted to address your concerns or whatever the case is, you don't feel as welcomed".*

Summary:

Georg Simmel identifies the qualitative meaning of individuality, as 'human beings being distinguishable from others' as positive and of value (Simmel, 1971). Valuing individuality, seeing the patient as a person, emerged as one important sign of respect. Seeing patients in a broader personal and social context, behaviors like listening and understanding issues specific to that individual patient and actions that demonstrate to patients that clinicians are paying them individually extra attention by spending additional time with them or going 'above and beyond' their professional responsibility contributed to patients believing that they were seen as an individual, not merely a patient. Additionally, patients thought that it was important to see their clinician as an individual and not just a medical provider. Knowing the clinician in a broader social context might reduce pre-existing hierarchical roles in the encounter, increase the level of rapport and sharing that patients describe as respectful.

4.1.3 Valuing agency - Validating patient's concerns and adapting care

The second analytical theme that was included in Table 7 was 'valuing patient agency', understood as the patient's capacity to influence their care in and outside of the encounter. For ease of reference, Table 9 lays out the initial and focused codes that

resulted in the 'valuing agency' theme. It was clear that patients' conceptions of respect are connected to feelings that they have some control over the decisions being made, or that they have some agency in decisions made about their healthcare. Twelve out of the fourteen patients connected respect to feeling that they contribute to decisions about their own health care. Patients believed that they contributed to their healthcare by agenda setting, by sharing their concerns with clinicians, by being accountable for their care and by sharing the responsibility for managing their chronic conditions with their clinicians. Finally, the importance of agency for respect was reflected in patients' descriptions of clinicians validating patients' concerns by offering solutions.

Table 9: Examples of codes that formed the 'valuing agency' theme

Initial codes	Focused codes	Analytical themes
Agenda setting, prioritizing Patient's needs are expressed Sharing responsibility for care Working together	Contributing to care	Valuing agency
Patient's concerns are validated Validating involves responding to and answering concerns Validating clinicians	Validating behaviors	

By expressing her needs and healthcare goals, Ayana believed that it is her obligation to contribute to the encounter and treatment planning, "*they don't know if I don't tell them. I'm very complicated and she understands that.*" Ayana's main healthcare goal is to attend a pow-wow in the summer and she believes "*if you don't have a goal to*

look forward to and if she doesn't know what the goal is, it's kind of pointless because at least she tries to help you get there". Twelve of the fourteen patients described respect when they shared their concerns with clinicians and clinicians listened and understood their concerns, enabling them to be addressed at that time. Prior to watching any of the videos, more than half of the participants, such as George an elderly gentleman with osteoporosis who was visiting his clinician for a check-up, responded immediately to questions about respect by emphasizing that it was the patient who influenced the agenda by, *"hearing what I've got to say versus whatever his agenda might be."* In contrast to George, Rachel reflected on disrespectful behaviors that stem from a clinician not factoring in her concerns, "*it's like sometimes, you could tell a doctor exactly what's going on, and it's like it goes in one ear and out the other, and they're off on some other track, not on what you were talking about."* Rachel further described aspects of her encounter where clinicians are 'rushing' or pressured by time constraints and this limits the ability of patients to contribute to the agenda in the visit, "*I feel very ignored cuz his mind is on everything else he's got going on, and I know that's a lot. I can understand that, but that gets very frustrating."*

Sharing responsibility for care was also described by patients as contributing to respect. For example, patients described respect when they perceived themselves to be equal partners in managing their chronic conditions. In answering how he conveys

respect to his clinician, Humphrey emphasized how important goal setting is to him so that he can hold himself accountable, "*listening and following through with the stuff that she says to me, …she always gives me a come back date so between now and January my goal is to make sure that I lose some more weight."* For Ayana, her clinician is "*all I got*" and she feels that if her clinician "*has enough respect for me to do that, I have enough respect to try whatever she needs*" and in this way Ayana believed that it was respectful of her to share the responsibility for managing her care outside of the encounter with her clinician. In the encounter itself, Lily felt that she was equally responsible for managing the time constraints of the encounter by being prepared with her list of concerns,

> "*I feel as though it makes a better use of our time, you know, I know that time is tight, and so I don't want to be taking a lot of time and then miss some things that I wanted to talk to him about."*

In describing respect, Margaret also felt that she shared the responsibility for managing the time constraints of the encounter efficiently to manage her care, "*I know that they don't have a whole lot of time either and so I think that you need to be respectful and come prepared, you know this is your health and you have concerns."*

For other patient participants, respect was evidenced when they felt that they 'worked' with their clinicians. An example was Helen and George who spent a long time discussing how they felt about being active participants in their encounters. They concluded that they have a role to play in their care alongside their clinician, "*you're a*

part of this, it's not something that I'm doing to you, we're here in this together." In Ayana's own words, '*working together*' was how she described her approach to managing her health, "*I might see something she don't because I live with it every day, but she studies what's going on so we kind of interweave and it works out itself*." Even before I introduced the concept of respect in the reflexivity sessions, Margaret described her encounter as respectful when she was able to participate actively in the encounter, "*I think that you need to be your own advocate in many ways and then hopefully get that exchange of ideas going, a mutual respect, both ways, you know it's a two-way street*."

Some clinician behaviors made patients feel validated, which I argue also reflects the connection between respect and agency. Patient's felt validated when clinicians discussed treatment plans with them in a way that made them feel as if they had exercised some agency over their healthcare. In some cases, patients felt respected because their clinicians adapted care to meet their concerns. Respect was described as patients exercising their agency when their concerns were factored into the treatment planning and decision making processes, as Oliver said, "*listening to what my concerns are and then offering possible solutions*" demonstrated that clinicians were being respectful. As Lily watched a video-recording of herself being invited to share her concerns during the initial history taking segment of the encounter, she could see herself explaining her main concern to her clinician, and noted how her clinician was listening to her and

understanding. She realized that he had understood her concerns because the treatment plan was adapted to refer her to a physical therapist for the pain in her leg that was not responding to medication,

> "*he was listening and, in my lay terms, I was trying to explain what was going on with this thing on my leg, and I think he was understanding it. …. He came back with questions that pertained to the things that I had said to him, and had a plan for what we would go ahead with in the future".*

Humphrey also described respect when his clinician offered a solution to his concern of when he should take his new medications. His clinician thought that he should take one of his pills at night, but Humphrey was not keen to do this as he takes all his other pills in the morning and thought that he might miss his evening one because it wasn't part of his usual routine. His clinician adapted the treatment plan to address these concerns. According to Humphrey,

> "*I thought that she compromised for what I wanted her to do otherwise you just have to take one pill every night ya know, versus all the others …it makes me feel good, there's a doctor that's supposed to be all-knowing and everything and then she will listen to some of the suggestions that I make to her about what's going to happen to me".*

Margaret's clinician also adapted her diagnostic testing to her personal context. Margaret could reflect lightheartedly on her clinician offering her a choice of how she could do a cardiac stress test. Margaret had explained that running is difficult for her. To accommodate Margaret's concerns, her clinician had suggested an alternative and

Margaret linked this flexibility in adapting the care plan to respect, "*We also came to the conclusion that we'd probably try for me to do the biking, and you know again I think that's very respectful."* Communicating with her clinician is how Ana believed that she could best provide the personal insight needed to come to a treatment decision. Without this contribution from patients, Ana felt that continuity of care would be affected,

> *"If you're the client or even if you're the doctor, without feeling like you're being validated or respected, you are not going to expand on what's going on. You're going to answer questions yes/no, and you're not going to want to be there or want to come back there*."

The majority of patients described the challenges of integrated care and the tensions with specialists when patients exercise less agency. For example, Humphrey attributed his new diagnosis of diabetes not to his primary care doctor but to specialists in the hospital whom he had seen when he fell and had a concussion. Humphrey was dubious about the diagnosis but did not sound like he felt that he could discuss it with them, "*they said that I have diabetes, I don't really think that I have diabetes but they know more than I know".* With his primary care clinician, Humphrey felt that even though his clinician did not change the treatment decision for diabetes management, she let him know that she had understood his concerns and explained why an alternative treatment was not medically advisable,

> "*well just the way she handles what we say and how she responds to what we say, I think she is pretty respectful of what we say to her. She seems to accept*

everything we say and then tries to turn it back in a positive way that she heard what we said."

Summary

'Patient agency and empowerment' can lead to better health (Street, Makoul, Arora, & Epstein, 2009). I argue that patients' descriptions of the importance of contributing to care and having their physician validate their concerns show how valuing agency is connected to respect. Respect is evidenced when clinicians take additional actions to modify care to include patients' contributions. Throughout patients' reflections there was also attention to the mutuality of the relationship and working together to manage patients' chronic conditions. Being respectful involves 'work' by both participants. Patients need to be able to share their contexts and their views on their treatment plans so that clinicians can have this knowledge and clinicians need to understand personal motivations and goals to adapt care to meet them. By framing respect as 'doing with' instead of 'doing to', patients and clinicians are sharing responsibility and working together as partners.

4.1.4 Valuing emotional work and affect - Feeling comfortable

The third analytical theme that was included in Table 7 was an emotional and affective element, 'feeling comfortable.' For ease of reference, Table 10 lays out the initial and focused codes that resulted in the 'feeling comfortable' theme. All the patients

described their emotions, feelings and the importance of 'feeling comfortable' in the encounter as dimensions of respect. First, many patients described their own affect or emotions as showing that that encounter was respectful. Second, patients cited their clinicians affect as also important. According to patients, both patients and clinicians could be affected and have a role to play in creating respectful environments. Finally, patients described environmental aspects of the encounter, the physical space, sound and intangible factors as contributing to their perceptions of respect.

Table 10: Examples of codes that formed the 'valuing feeling comfortable' theme

Initial codes	Focused codes	Analytical themes
Expressing Emotions Feeling at ease, not threatened Being open, ability to open-up	Personal affect	Valuing Feeling Comfortable
Caring Being non-judgmental Being a Friend	Clinician affect	
Valuing an in-person dynamic Developing Rapport Understanding the role of humor Affecting comfort levels via verbal and non-verbal cues	Environmental affect	

Patients' descriptions of respect suggest a dual responsibility; patients need to be open with their clinicians and clinicians also need to 'work' at conveying respect and creating an environment where patients felt comfortable enough to share their stories. Without this 'emotional work' respectful attitudes may seem inauthentic. In one of the

encounters it seemed obvious to me that although the clinician said and did expected respectful behaviors, the patient was aware that it was an act. Ana's clinician started the encounter by asking if she had any concerns. Immediately as she began to speak she was interrupted to re-direct the discussion and outline the clinician's agenda for the encounter. Ana reflected on the level of comfort she was (not) seeing in the edited clips of her clinical encounter and highlighted the consequences for care of not feeling comfortable,

> "*He wanted his answers to his questions, as opposed to he wanted to hear what I had to say; and so to me, that was, you know, just a little uncomfortable. As far as being respectful, I felt like I answered his questions. I was giving the doctor what he wanted … but if you don't feel that you are as comfortable, I don't think you're going to be as open as far as what's going on, you may not elaborate, and I think that helps in terms of openness."*

Firstly, patients saw their feelings as central to defining whether an encounter was respectful. For example, patients felt that part of a respectful encounter was one where they could share and be open. Oliver was unique in the study as he readily shared with his clinician that he had switched medications on his own, because he preferred his wife's medications. He believed that he needed to be open with his clinician, "*I have the strong feeling that it's best to be upfront with your doctor. If he's going to help you, you can't hide things*." Jean also felt that she shows her clinician respect by "*being honest to my feelings, you know, how I do feel about it"* and this occurs when she's comfortable with him. Lily also concurred that feeling comfortable meant, "*at ease, not threatened*". Not

all patients felt comfortable or relaxed enough to be open and upfront with their clinicians, even if they wanted to be. For example, Rachel, after reviewing part of the encounter where she was discussing how she felt about her brother's recent death and seeking counseling for trauma experienced during her childhood, reflected that it was unusual to feel that she could be open:

> *"that was more natural and relaxed. Cuz normally, when you sit with a doctor, you're so guarded about what to say, you know. That's the first time it did not feel that way. And I think Dr. (intentional omission) actually made me feel that way."*

While watching the history taking part of her clinical encounter Margaret also described how feeling comfortable allowed her to feel safe enough to ask more questions,

> "*he put me at a comfort level where I felt at ease as far as asking questions. I wasn't afraid to ask the wrong thing you know so to speak. … obviously I was comfortable enough you know to let my guard down."*

Secondly, patients also described how clinician's affect and perceived emotional attributes contributed to a respectful encounter. Primary among these was a sense with patients that caring was respectful. Julie, in responding to questions about clinicians at the practice stated, "*I think to go into the medical field you have to be caring and care about other people.*" Ayana similarly equated a sense of caring with respect, "*when you're taking care of somebody, you have to have a lot of respect in order to help them.*" Finally, Lily who had had a clinician for forty years who recently retired, was looking for

someone that she could also feel comfortable with. After reviewing a video-recording of her encounter where she and her clinician discussed plans for her next visit, Lily concluded that her clinician's behaviors had been kind and considerate such that she felt comfortable:

> "*I think by the end of the hour that I spent with him, I felt that I would be comfortable with him, and so I was willing to go ahead and schedule my fall things, with him. He was very kind and considerate during all of that. So, I felt comfortable."*

Some patients felt that the clinician should be a friend as a sign of respect. For example, Oliver described clinician behaviors such as "*professionalism and friendliness that makes you feel comfortable*". Another example was given by Sonia who described her clinician like her two best friends and reflected, "*I feel a closeness with her. I feel like she's very sincere and that she cares about you".* Rachel also described what was respectful to her as, "*this was more like a friend. This was more like getting to know the patient, it makes them feel more at ease and relaxes them*." Besides being kind and caring, and being a friend, Rachel identified other clinician behaviors that could make a patient feel comfortable, such as 'taking time', "*well, for one, she is taking time to really see if the patient needs to talk about something, she asks if there's anything else."*

Patients also saw respect reflected in their clinician's level of comfort. Humphrey, for example felt *"I think we are both comfortable with each other ya know, she seems a*

little relaxed too…so she's pretty comfortable with us too." Sonia felt similarly, "*Right away, when she walks in the room, I get the sense that she's comfortable seeing me too."* Ana agreed that it was important part of respect for her clinician to feel comfortable*,* "*I think it's really important that there is a sense of respect, … for the doctor to feel comfortable."*

Thirdly, attributes of the encounter itself were described by patients as influencing their level of comfort. The familiarity of the physical space where the encounter was held came to mind when Oliver was asked to reflect on respect and his recent visit, "*I felt comfortable just because I've been in this setting a number of times before*". In other reflexivity sessions, sound and verbal and non-verbal cues, were highlighted by patients' descriptions of the encounter as contributing to a sense of feeling comfortable. For example, Sonia described the rapport that she has with her clinician as "*making it easier to talk with her*" about very personal issues and Margaret placed value on in-person dynamics and non-verbal cues as important, "*I prefer personal interaction, you just read people differently. You are looking at them and you are seeing how they are reacting to what you are saying*" when she was describing what was respectful about her encounter. One patient's description of non-verbal cues affecting respect in the encounter particularly stood out because of the depth of feeling ascribed to the description. Ana was

not comfortable and felt that her clinician should have been able to notice her body language and change his practice style to create a more comfortable environment,

> "*I think body language is important, and maybe it should be more important on his end than my end (laughs), but I think if if he looks at me or looks at the patient as they're having a conversation with him and they're turned away from them, you know, he needs to maybe change his line of questioning or maybe take a softer tone or whatever it is to help them feel just a little more comfortable*."

Summary

Descriptions of 'feeling comfortable' were related to respect in various ways. One of the ways was how patients perceived they felt or were made to feel in the encounter that allowed them to open up to their clinicians. Another way was through 'emotional work' where clinicians could be following a prescribed pattern of behavior that seems respectful such as being friendly, kind and caring or it could be through authentic interactions where a comfortable environment is created for patients to open up and share their personal concerns, and where clinicians were also comfortable enough to be open to patients. From patients' descriptions of respectful encounters, the work of creating a comfortable environment is a shared responsibility. Clinicians can take certain actions to create a feeling of comfort but patients also need to feel comfortable enough to open up and share with clinicians. Clinicians also need to feel comfortable to ask questions and to share their patient's concerns.

Conclusion

According to patients, respectful encounters occur in a comfortable sphere within the context of a partnership where patients feel they are prioritized and seen as individuals and where their concerns are validated and clinicians adapt treatment to meet their patient's concerns. To create a respectful space within the encounter patients highlighted how fundamental it is to share their personal stories and for their clinicians to share some of their personal lives as well. Patients felt that clinicians prioritizing their own agendas over the patient's and being limited by time constraints would impact the degree of respect in the encounter. Being respected meant that patients were comfortable enough to open up to their clinicians and to trust their treatment advice. The 'work' that both patients and clinicians do in an encounter to have authentic relationships where they can respect their individuality as well as their efforts to partner to improve patient's health may result in the need for an increased capacity to make sense of what is happening in the clinical encounter. Working together fosters relationship building, continuity of care, and adherence.

4.2 Question 2: How do clinicians describe respect in the clinical encounter?

The data used to answer research question 2 emerged from sixteen video-reflexivity sessions with fourteen clinicians. Given time constraints, one clinician participated in three shorter sessions. Sessions ranged from 25 minutes to one hour. Clinicians were mostly female (57%), white (78%), and have been practicing primary care medicine for between one and twenty-five years. The institution plays a significant role in clinicians' descriptions of respect. Within the primary care internal medicine department where the study took place, clinicians work in a team-based practice with a panel of 500-600 patients. All the clinicians in the study highlighted the role that continuity of care plays in relationship building, within the context of their present practice where they cannot feasibly have a relationship with the hundreds of patients in their panel. Moreover, given pre-existing time constraints and institutional mandates for entering orders in the electronic medical records, many clinicians found themselves developing strategies to be efficient at work, regardless of whether these behaviors were respectful. Indeed, some clinicians described a stage in their careers where they are acutely aware of being burnt out. Clinicians described respect for their patients and for themselves within the context of the patient-clinician relationship and noted that where they had relationships with their patients, they cared more and were willing to go the extra mile in ways that reminded them why they chose the medical profession originally. This reminder, 'retaining the sparkle' was one example given to mitigate burn out.

Themes of Respect

In the first three reflexivity sessions, I began with open-ended questions about patient centered care and the clinician-patient relationship in general. In the following eleven reflexivity sessions, the concept of respect was introduced immediately to (1) ensure that what I as the researcher was attributing to clinicians as respect was accurate and (2) as an expediency measure as clinicians seemed to be more time-constrained than patient participants. From both sets of reflexivity sessions (open-ended and framed within the context of respect) clinicians described their perceived role as doctors in the encounter and actions that they take to be respectful. As shown on Table 11, initial coding themes are mapped onto five focused themes: seeing the patient in a broader social and personal context; caring for the individual; validating behaviors; working together; and being efficient. I argue that these can be summarized by three analytical themes: valuing the individual, valuing agency and valuing feeling comfortable. As respect is co-constructed in the encounter, it was not surprising that the three emergent themes from the clinician data are very similar to patient themes. There was one unexpected difference. Clinicians described an underlying motivation to be respectful, framed within institutional constraints and tension, the need to be efficient, which patients did not describe.

Table 11: Initial and focused codes that formed the analytical themes

Initial Codes	Focused codes	Analytical themes
Patient as person	Seeing patient in broader social context	Valuing the individual
Accepting patient as they are		
Personalizing care	Caring for the individual	
Agenda setting	Validating behaviors	Valuing agency
Validating the patient		
Acknowledging patient's concerns		
Sharing responsibility	Working together	
Sharing expectations		
Treatment planning		
Feelings and affect	Being efficient	Valuing Feeling Comfortable
Strategically creating a comfortable environment		

4.2.1 Valuing the individual

The first analytical theme that emerged was valuing the individual. For ease of reference, Table 12 focuses on the codes that formed 'valuing the individual'. Clinicians described seeing the patient in their broader social and personal context by viewing the patient outside of the medical encounter not only as a patient but as a person; and accepting the patient as person where they are. Descriptions of caring for the individual included personalizing care to meet their patients' needs. In this way, clinicians described respect as making the encounter about the person in the room and adapting care based on individual patient's values, concerns and priorities.

Table 12: Codes that formed the 'valuing the individual' theme

Initial Codes	Focused codes	Analytical themes
Patient as person	Seeing patient and clinician in broader social context	Valuing the individual
Accepting patient as they are		
Clinician as person		
Personalizing care	Caring for the individual	

An example of seeing the patient in their broader social context was given by Claire who said, "*the most precious part of getting to be her [Ayana's] doctor is really knowing who she is as a human being and then helping her to achieve optimal health through that lens*." Clinicians like Diana felt that it was necessary to see each patient as a person within their own complex personal contexts. Diana described using an approach grounded in her spirituality that allows her to see patients as persons, *"to be present to that patient, for me, it's to really look at that patient as if that's somebody, I call it recognizing a presence."* For other clinicians, such as Adam, it was important to hear people's stories and to accept patients where they were on that day, with no judgments of their health choices, "*we get patients from all walks of life, and I pride myself at meeting them where they are at."* Alice also described respect as accepting patients as they are, *"I have used the term "universal positive regard" so you meet the patient where they are and you don't judge them for being where they are you know you just accept them as they are."*

Patrick defined respect in a similar accepting manner, framing healthcare within each patient's individual social context,

> "*respect is a sense of acknowledgement of the patient's perspective on their life and their health and their illness and just recognizing that, you know, that has meaning, and we honor that and maybe there will be an example here where, you know, this patient does or doesn't follow certain pieces of advice but to just understand that in their life story they're making the best choices they can."*

Accepting that each patient is a person within their own social context helps Patrick to understand the choices that patients make. After discussing the options that his patient chose in the video clip that we were watching, Patrick further concluded that treatment will be different given individual patient contexts,

> "*those are reasonable decisions that reasonable people make. They're different with the same information. You're asking about respect, and it is honoring different choices that people make given the same set of information because their lives and philosophy are different."*

Through storytelling patients could often share their goals and values in ways that enabled clinicians to care for them as individuals and to make personal decisions instead of medical decisions based on symptoms alone. In one of the earlier reflexivity sessions where participants were asked open-ended questions, John discussed how getting to know patients and the complexity of their lives was important,

> *"you get to know the person and their values and so I'll treat any of my patients with the same illness for example very differently depending on their framework about how they approach health and the disease."*

Like John, Kate highlighted the consequences of understanding the patient's values and the complexity of their personal lives for decision making, "*what we're bringing together is the fact that I have known them a long time, that I have a feel for what structure they have in their family."* In contrast, if Kate had not had the benefit of getting to know her patients' broader personal and social contexts, she reflected, "*that's harder, I mean it's making a medical decision as opposed to personal decision."* Without having the time to get to know patients in their broader contexts Adam concluded, "i*t's hard*." Adam also described his practice style as getting to know the patients in their personal contexts more so than focusing on their symptoms,

> "*many of the patients that I see, I try to get them to tell me about their day and what they do. Other providers are very disease focused. I think the patient describing how their life goes is a window into telling what they might be capable of and desiring."*

One clinician, Andrea, also described respectful behaviors in the encounter as including helping the patient get to know the clinician as a person by sharing personal stories because it:

> *"makes me more of a real person, because I share stressors too of something that is going on in my life. I think that it's as important for patients to see me or their provider as someone who can understand day-to-day social concerns or emotional stressors and helps us connect on a personal level. It helps smooth the way into difficult decision making about their health."*

Clinicians also described respect as caring for the individual by going above and beyond in their care for those patients. Unfortunately, it is not always feasible with such large panels of patients to have this relationship, and as Kate commented, care can often be more medical than personal. Another example of making personal or medical decisions when caring for an individual was given by Steven, a clinician who was reflecting on his teaching and administrative roles as well as his clinical responsibilities. Steven acknowledged how he feels about patients who he has a close relationship with compared to those that he does not, and how this affects caring for them:

> *Steven: [having a] relationship, I find those to be most rewarding for me and you feel really like you're involved in who they are as a person as opposed to just as a patient. I think it makes you more invested in their healthcare too because I feel like oh man I really know this guy and I want to make sure that he gets the right care.*
>
> *Researcher: and what about those that you don't really know*
>
> *Steven: well it's not that you don't do the best but you are not as invested, you still do everything that you need to do but you are a little bit less apt to make the extra phone call not intentionally but unintentionally you are like okay I did what I needed to do.*

Summary

Respect as 'valuing the individual' was formed from two ways of looking at respect in the clinical encounter, as clinicians seeing patients and themselves as persons in their broader social contexts and caring for the individual that they have come to know. Without this knowledge of the person's broader context, clinicians described a less

respectful approach where medical decisions are made over personal decisions. In almost all instances, clinicians favored delivering care that was respectful of the individual but they acknowledged that this is not feasible with such large panels of patients and limited time constraints of the encounter.

4.2.2 Valuing agency

A second theme that emerged in clinicians discussions of respect was valuing patients' agency as shown in Table 13 when clinicians described such validating behaviors as incorporating patients' concerns through agenda setting and acknowledging and validating those concerns by adapting care to include them. Moreover, clinicians felt that they worked together with patients when patients shaped their care by partnering with clinicians to come up with treatment plans and by sharing responsibility for their healthcare.

Table 13: Codes that formed the 'valuing agency' theme

Initial Themes	Focused themes	Analytical themes
Agenda setting	Validating behaviors	Valuing agency
Validating the patient		
Acknowledging patient's concerns		
Sharing responsibility	Working together	
Sharing expectations		
Treatment planning		

Clinicians described how they validated patients' concerns in several ways, including recognizing patients' contributions to the encounter in setting the agenda. The agenda is essentially a roadmap of the priorities that either participant would like to set for the direction of the visit. The clinician and patient agenda need not be the same and are very often different, leading to unnecessary tension in the encounter. At the very beginning of Patrick's reflexivity session, before he had watched any of the videos, he emphasized letting the patient set the agenda as important,

> "*As physicians, we have our agenda, because we know the medical problems; we know which things need to be followed up on and what things need to be done, and it's easy to let that kind of run the visit because it's the medical piece. But from the patient's perspective, they're maybe not as focused on that and more just what the issues are of their day and how the medical care influences their life."*

Like Patrick, John also discussed letting the patient set the agenda because what his patient had to say was important for her care,

> *"I think that I did a reasonable job of letting her set the agenda. That was a time when it was critical to let her keep going, I mean she was doing all the talking just then in that part that we just watched. It was valuable for her, she was telling the whole process from start to finish, very valuable information so I just make sure and keep my mouth shut".*

After watching some of the video-recordings of their encounter, particularly the beginning, John further described respect as co-creating the agenda which was preferable to him as the clinician than dictating what the agenda should be,

> *"through multi different ways soliciting patient values related to that encounter is an important indicator of respect. I mean it's pretty clear that co-creating an agenda rather than a more paternalistic approach, that's obvious."*

Validating the patient also involves prioritizing their concerns. By letting the patients lead in the encounter, Dianna provides a space for patients to prioritize their concerns and to influence their care,

> "*the fact that he was transitioning to want to talk about the blood sugar so that was when we started to talk about the blood sugar and so I feel like it's sort of like dancing, it's like following the patient's lead as I have this list of things that I want to get through but following his lead and then being able to be flexible."*

Clinicians' descriptions of respect as validating behaviors were often described in conjunction with an underlying tension. Ralph discussed the tension,

> "*I guess you gotta figure out their agenda and you gotta merge it with your agenda because we have an agenda too ya know. … So I mean I am trying to fit my three or four-part agenda underneath whatever she wants to talk about."*

Another way of validating concerns was letting the patient know that they have been heard, that the physician understood and that actions would be taken to address these concerns, whether or not the patient's health care is ultimately influenced. For example, Patrick thinks that acknowledging the concerns of his patients was essential, "*I*

think if there's some acknowledgment of the problem and some plan to do or not do something that's better than, you know, not addressing it at all." When Diana was asked how she plans for the future with her patients she replied in a similar fashion to Patrick, highlighting the need to have patients influence their treatment plans, "*I think it's customized based on their needs."* A further example of validating behaviors was given by Nick who demonstrated the consequence of the patient prioritizing their healthcare in the encounter,

> "*that kind of goes back to our video clip, How's that impacting the patient? And he says, well it really disrupts my sleep, and it's like oh, okay. We can focus on that. I'm worried about gastric cancer, and he's like—Ah, I'd really like to get a good night's sleep."*

Clinicians employed specific strategies to communicate to patients that their concerns were heard and that the patient had a say in their care. John used the patient's storytelling to reassure them, in their own words, about their care,

> *"I was using her words from the history so that the first thing that she said was 'I have a vascular problem', and so after I examined her I reflected that language here to reassure her that she does not have a vascular problem and to alleviate this concern."*

At the end of his clinical encounters John used a 'safe' strategy when he asked the patient "*is there anything that we can chat about today that we didn't?"* While John felt that question conveyed to patients that they are involved in their care, *"to make sure that they feel that they've been heard and that they can kind of acknowledge that by answering that*

question that they've been heard," in reality, John acknowledged that rarely would patients add any new concerns at that stage of the encounter. Alice also discussed a validating strategy that she uses to encourage patients to influence the direction the encounter would take,

> *"I try to sort of say 'sorry you are going through that', or 'that must be hard' or validate the emotions; you try to sort of figure out you know is she asking to go there or is she not, because sometimes they just have to share and cry and you may not achieve anything else in that visit and that's okay."*

Steven also provided an example of his validating behavior that saw his patient influence the outcome of the encounter when he agreed to a surgical consult that he did not think was necessarily warranted,

> "*While I don't know that it will be helpful it's not likely to be harmful either and so usually what I am trying to be is respectful… here are the options do you want to give it time or do you want to get a CT scan?"*

On the other hand, Steven also discussed how validating his patients' concerns is a deliberate strategy on his part and a way of showing respect. Steven is cognizant that his behavior is motivated by more than respect. It is a purposeful way of affecting his patient's satisfaction,

> "*Your choice at that point is to say 'oh sure' or 'okay' but if I am the patient, that doesn't feel like my doctor is really paying attention or listening or going to investigate that and so I think my saying 'okay let's take a look at that, tell me more about that, tell me what's going on' that's giving them the opportunity to*

then say I am going to listen to you about this problem, and I think it opens a door for them to know that he is going to take me seriously when it comes to this."

Another example of validating concerns as an overt strategy in the encounter was described by Sue in direct response to my question of "*as we go through the videos is there anything else that you see that can convey respect*", Sue replied with a response that did not seem at all respectful of patients' agency in the encounter, but proved to be 'efficient' for Sue as the clinician as by listening she can convey validation, which she knows is important for patient satisfaction.

"*let them speak out, it'll take a while, it will feel like a lot but two things can happen. One they feel validated because that was their time that they bought and the service that they're paying for, and the other, you give them validation, a sense that you listened even if it's a rant. I think it's efficient, it serves a number of purposes all at once.*"

Finally, respect as valuing agency was informed by clinicians' descriptions of working alongside patients, sharing experiences and coming up with a treatment plan together. An example of patients contributing to managing their care was given by Ralph who noted that patients such as those who bring a list of their concerns to the encounter demonstrate commitment, "*because you are organized and you have questions you know, I think that's good, I think that shows they are invested in what they are doing."* Diana also reflected on the role that her patient plays in being mutually responsible for his care,

"*He was newly diagnosed with diabetes so there has been a lot for him to adjust to and he had been working on some different things. I feel like he had achieved,*

> *if I recall, some of these things, he is already starting to adopt some of them but not all of them, so it was fun to see that he's on the path and then it was really fun to see his interest in understanding the diet more and his wife being present, and them engaging."*

Alice consciously involves her patients in their care by celebrating their successes and holding them accountable,

> "*it is also very important to do a little bit of motivational interviewing…that's important that you are reinforcing what they are already doing instead of just loading on new tasks and not crediting them for what they have already done… It is very important especially with patients where they are not making great progress to sort of give them a point of accountability."*

Alice also asks her patients to hold their clinicians accountable for follow-up plans, "*Of course the responsibility is primarily ours but we want to share that responsibility with the patient."* Alice goes even further by involving her patients in any decisions that are taken, so that they are taken together, "*I usually won't order things without talking to my patients. I do try to involve them in those choices and not just say I am going to do this."*

The importance of giving patients agency was also evident in clinicians' descriptions of involving patients in decisions pertaining to their health. Patrick was one such clinician who said, "*if you're communicating respect, I think that allows them to feel like they can make a decision based on their goals and values and not on what they think the doctor wants."* Steven reiterated the importance of collaborating with patients in their decision making,

> "*The patient is an integral part in the care of the patient and so they have to be a part of all of the decisions that get made regarding their healthcare and the way that I try to approach it is that I think about us as a team and that we together have to come up with what is the best plan for that patient and part of that means that you have to understand what is important to them what their wishes are, what their values are, cultural background, all these things to really understand what is going to shape what they want you to do so you can help them come to the right decision for their health."*

Nick was unique in the sample of participants when he deliberately involved patients directly in their treatment plans by dictating in their presence; primarily so that they could contribute at that stage to anything that had been agreed upon, but also as a time-saving mechanism so that his dictations were completed before his next encounter.

> "*for the patient, it allows them to hear the plan one more time, and my patients are so used to me dictating in front of them, they will correct me while I'm dictating. I think it improves the accuracy of the medical record. It involves them in what we do, so they kind of see everything that goes on in that visit."*

Summary

Clinicians described respect in ways that demonstrated that they valued patient's agency, their ability to influence the course of the encounter through agenda setting and prioritizing their concerns, as well as by having their concerns validated such that care plans were discussed and often modified to accommodate patient's inputs in the encounter. Working together to affect care within the encounter was complemented by descriptions of respect when patients shared the responsibility for their care with

clinicians outside of the encounter, as they manage their conditions in their day-to-day lives. While there were many descriptions of respect through validating behaviors and working together, some did not ring true as clinicians seemed preoccupied with being efficient, strategically being respectful to influence patient satisfaction with the encounter or employing respectful strategies to better manage their time in the encounter.

4.2.3 Valuing Feeling Comfortable

The third theme that emerged from clinicians' descriptions of respect, 'feeling comfortable' is detailed in Table 14 and underscores respect as a balance between how patients and clinicians feel in the encounter with clinicians being strategic and efficient in creating a comfortable environment in the interest of expediency for example.

Table 14: Codes that formed the 'valuing feeling comfortable' theme

Initial Codes	Focused codes	Analytical themes
Feelings and affect	Balancing emotions with efficiency	Valuing Feeling Comfortable
Strategically creating a comfortable environment		

Clinicians described respect as their patients feeling comfortable in the encounter. When Teresa was told that the study was about respect and shared decision making, she described respect as mutual and shared especially when she practices alongside her patients, "*I wouldn't want it to be one-sided. I would hope that my patient would feel*

comfortable and confident enough to be able to participate in the conversation." After further probing on what 'comfortable and confident' means Teresa emphasized that it meant patients being able to "*speak up especially if they don't agree*". Like Teresa, Ralph also placed value on his patients speaking up and sharing with him. Ralph noted that it was clinically useful when patients felt 'at ease' and tell him what's going on.

According to clinicians, respect was their patients feeling comfortable as well as clinicians themselves being comfortable. Ralph noted how difficult it is to be comfortable initially when there is a 'fear of the unknown' with new patients, as such, his goal is to get to know them so he can reduce this tension in the encounter, "*Until you know someone, then you are more comfortable with them. There's a tension. When you get to know someone's history you can relax a little bit.*" Steven provided another example by describing feeling comfortable in terms of the clinician being comfortable with his own practice as well as comfortable in the relationship with their patients,

> "*I think to me being comfortable means that I have to be confident that I know what I am talking about in that room certainly part of being comfortable or what bothered me when I first started practicing was that I didn't know if I knew the medicine and so it made me very anxious when I would go see patients. That took a while to be comfortable with being uncertain."*

After watching numerous video clips, Steven described how after ten years of experience, he now feels more comfortable in the encounter,

> *"watching me interact with this patient feels like this is what I do, it feels like that's my wheelhouse this is my operating room you know this is where I am comfortable is talking with people getting their stories and getting that information from them and you know it just kind of feels, it feels like my routine."*

For one clinician, feelings of discomfort emerged when he felt that he was not respectful of his patient. While Steven was reflecting on how his comfort levels have changed over time, he watched a video recording of the introductory part of his encounter where he invited his patient to share her concerns and then interrupted her. There was an evident tension in Steven who wanted his patient to be comfortable but by trying to control the direction of the encounter, he contributed to his and her discomfort,

> "*It feels a bit uncomfortable because what we are taught is let the patients talk. Just let them go and yet we are also taught make sure you organize and control what we are talking about and it is so hard to balance that and that is what I was struggling with. Watching it made me feel uncomfortable again. What I am trying to do there is prioritize things but it is frustrating because sometimes I feel like I need to interrupt people to get that done."*

Steven linked this balancing act to respect for his patients when he said,

> "*As I think about respect for the patient I think that I am going to value their beliefs and values, what is important to them. I'm going to weigh their concerns on an equal footing with what my concerns are. … It takes a while to become comfortable with that and to just let things go where they are going to go and not have control over all of that."*

There was another instance during the encounter when Steven was probing his patient about her sexual health when he again observed that she may have been uncomfortable.

Steven then discussed strategies that he could use to make patients feel more open and comfortable,

> "*She is not looking at me that much, I don't know if that's just her style or if maybe she is uncomfortable. … I really want to make people aware that it is a safe space to talk about their issues and that's what I always tell people that's why I am here, if people did not come to me with their concerns I would not have a job."*

John seemed to agree that creating a comfortable environment could also involve balancing efficiency with respect in the encounter,

> "*I felt comfortable too, you know I think it's important, it's this balance of maintaining just sort of good and inviting social habits so that people feel that they can open up to you and not hold anything back. But at the same time have that constant efficiency mode at the back of your mind where you know exactly where you are going next."*

The relationship between respect and feeling comfortable as described by clinicians also has implications for clinician burnout. While the clinical encounters may become standardized, for some clinicians, like Teresa for example, making personal connections with patients is a way of retaining the 'sparkle' of the job and avoiding clinician burnout,

> *"as a physician, you can kind of burn out, you know, because I think it's ultimately those personal connections and remembering that people are people is what is compelling to kind of continue on; and if you don't have that and it just kind of becomes routine and standardized, it just loses its luster a little bit; even though it's important, it just doesn't, it kind of, the sparkle goes away."*

Another way that clinicians can recognize their feelings in the encounter is to be aware that while is it important for patients to respect their clinicians, it is just as important for clinicians to respect themselves. Andrea spoke about laying 'respectful boundaries' between visits and between her and her patients so that she does not burn out and end up disrespecting the very patients that she wants to care for,

> "*I also know that she appreciates our relationship so that she respects me as a person as well and as a care provider you know caring for her.… I think that you always need to be respectful but in that to lay respectful boundaries (laughing) and that's really hard. How to always be respectful of my patients both in encounters but between encounters and to do so in a way that will make for a long, good relationship with them in a way that's do-able. I want to make sure that you don't get burnt out and you can stay in this for the long haul and not disrespect them"*

Clinicians described various strategies that they employ to create a comfortable environment for their patients, in addition to different motivations for creating a feeling of comfort in the clinical encounter. At the very beginning of the encounter, Teresa recognized that the space within which the encounter occurs is important and is most often related to respect by feelings of comfort. One way in which Teresa acknowledges that she needs to respect this physical space was to view the appointment room as the patient's space for which she needs permission to enter. Teresa believes that she can create a comfortable space by, *"Knocking on the door, so it's not me charging into their space."* Realizing the importance of feeling comfortable, other clinicians, like Patrick for

example, described various strategies, including ‘taking time’ that they employ to create a comfortable space for patients to share their concerns,

> *“Well I think, you try to be open-ended in terms of identifying their concerns for the day and trying to spend a little time, if you have the time, to understand how their concerns are kind of intertwined with their daily life and spend a little time with what their concerns are and what their barriers are following advice and those sorts of things.”*

Another strategy that clinicians used to help their patients feel comfortable was to create a safe environment where patients are not being judged. After watching a video-recording of her patient saying that she was ‘gun shy’ to ask questions, Alice realized that creating a safe space is useful for patients but also for clinicians as it could allow patients to question and disagree with treatment plans that they did not support,

> “*patients should feel safe to ask us anything…. We need to be mindful of that, that we allow them to ask questions, allow them to disagree with us and for her that's probably very important especially if she's afraid of asking simple questions she will probably even feel more afraid of saying oh I don't think that's a good thing for me or something. … So I think that is what creates that safety, that they don't feel judged and labeled you know right away.”*

Another strategy Alice uses for creating a comfortable space in the encounter for both patients and clinicians is sharing personal stories,

> “*If there is a common experience I share with my patients. I find that very effective that you reflect back oh I have done that, because that sort of puts you at their level, if you have a shared experience that's a connector, I use that quite a bit.”*

Similarly, Kate employs this strategy to humanize herself as the clinician in the encounter,

> "*I tell my patients a lot of stories, I tell them my mother has had half of their diseases. My sensation is that patients like that sense that somewhere in your world you have experienced this. It is some way of making us less scary or less doctor in the room and more human."*

Wanting her patient to feel comfortable also influenced how one clinician changed her treatment plan. Andrea reflected that her patient did not make many requests in an encounter and when the patient did make a request Andrea modified her recommendation to accommodate the patient's comfort levels, "*I had said three months and so when she said 6 weeks, I think it was her not feeling comfortable waiting three months and so I wanted to meet her request because she doesn't have a lot of them*."

Summary

The final theme of this results section described mutually respectful behaviors where clinicians are cognizant of the importance of creating a comfortable environment in the encounter so that patients can feel safe and open up with clinicians, whether to share their personal stories or to disagree with the treatment plans. Clinicians also realize that they themselves feeling comfortable is critical to how they want to practice medicine but that there are often underlying tensions that become evident when clinicians want to create a certain context in the encounter that is challenged by how clinicians have been trained to

control the direction of the encounter and by time limitations. Clinicians working to create a comfortable environment was a necessary condition for other aspects of respect to be evident. For example, providing agency to patients is possible when patients feel comfortable enough to challenge treatment plans. Seeing each other as individuals is also possible when patients and clinicians are comfortable in the encounter such that patients are given the space and time to share their personal stories and clinicians can begin to mitigate some of the challenges of feeling burnt out.

Structural challenges and institutional barriers

Clinicians are aware of the institutional challenges that affect their ability to be respectful in the encounters. This is especially true in instances where the challenge is beyond their control. For example, in the implementation of new information technology and established time limits for the encounter. Another example given was reimbursement structures which inhibit follow-up visits with established patients. In most of these instances, clinicians referred to their internal voice telling them what they should be doing while they presented a professional façade to the patient. Clinicians' reactions to some of these challenges were strong and often delivered emotionally. An awareness of the institutional barriers that they faced resulted in clinicians strategically being respectful to overcome these challenges.

Most clinicians acknowledged the role of the computer in the encounter as challenging. Meeting their institutional obligations to have orders entered while the patients are in the encounter, often resulted in additional tension for clinicians. It is difficult to balance being attentive to patients and accurately enter information into the electronic record. This imbalance often results in tension that clinicians observed while reflecting on their encounters. Ralph for example emphatically described how much he dislikes entering orders in the encounter and the resultant tension that he feels,

> *"it's hard to act like you're paying attention to someone when you are on a computer, because you're not, I mean I can't do two things at once really well. I can either figure out what's going on, on the computer or I can listen to them. … I am trying to figure out how I would describe my posture. It like if you took something really tense and then relaxed it a little bit."*

Another example of balancing the tension that entering orders creates was given by Kate,

> "*I hate it, but often you will see me apologizing ahead of time. Literally I cannot do it without concentrating anymore, it has gotten so complicated and so I have to give permission to tune them out for a moment and do it right or else all hell breaks loose which is a very unfortunate state of affairs."*

Steven is more explicit with his patients and his personal strategies for addressing the computer in the encounter,

> *"I don't usually sit under my desk I move to the side partially to keep myself from looking at the computer. I move myself over so that the patient can tell that I'm paying attention to them and not the computer. It is so easy to get sucked into all of the distractions that I intentionally try and engage with all of my patients as a*

reminder not only for them to understand that I'm focused on them but for me as a reminder that this is where I am focused on right now."

While Claire observed the tension that she felt on the computer, she was also able with further reflection, to highlight ways in which she could have been more respectful to her patient.

"So I could see this tension. I remember talking to her and I remember being really interested and wanting to hear more but also the tension that we need to get her orders in. I feel like I could have, to show additional respect, I could have left the computer and moved my chair closer to her."

Like Claire, Sue appreciated the reflexivity sessions as it allowed her an opportunity to see how she could overcome the institutional barrier of entering orders into the computer,

"I think it's helpful because we never really see ourselves and one of the things that it helped me be more mindful of is that as I multitask sometimes I turn away from them and I probably would make eye contact more with them. I think that's probably something that I could do better."

<u>Time:</u>

Set time limits for the clinical appointment often resulted in additional internal tension for clinicians who may have other patients waiting or administrative roles that they have to fulfil. For example, Adam is keenly aware that there are institutional expectations that he needs to meet outside of his clinic time and this leads to additional tensions for him when he is seeing his patients.

> *"as I watch this visit, this is a long visit for me, and I am always behind and there is a tension there and it's not easy. This visit had a pretty, I would say a fairly large degree of personal contact and you know, you just can't be that to every single person. That's the challenge that I find. You know because I come in and I've got 30 messages and a full slate of patients, that's just not, I am not going to be here until 10 o'clock."*

In elaborating on the cost to himself of delivering extra time and care, Adam remarked "*yeah, yeah, we can't bill for it*".

Sue realized that there is a finite amount of time in an encounter and she must make decisions about whether to go beyond that time. The language that she used was very defensive and it seemed as if Sue felt powerless in addressing the challenge of time. In her reflexivity session Sue says that she had to end the discussion, but in the actual encounter she stayed an extra ten minutes discussing something that the patient introduced at the end of the encounter.

> *"sometimes I feel baited to spend more time there and I either have the time or I don't, and I have to decide. So I didn't. I am not sure that spending more time talking about how you were feeling, will necessarily change the plan, in my head, that's what I am thinking to myself."*

Conclusion

Clinician's descriptions of respect in the clinical encounter, recognizing participants as persons, personalizing care, prioritizing concerns, creating a comfortable space, validating and collaborating are closely aligned with the themes that emerged in research question 1 on how patients describe respect: valuing the individual (patient as person), valuing agency (validation), and valuing feeling comfortable (emotional affect). However, the underlying motivation for creating a comfortable space in the encounter in which patient's concerns are prioritized and validated, where collaboration leads to personalized care differs for patients and clinicians. Throughout the encounter clinicians are acutely aware of structural challenges to their desire to be respectful of patients and their concerns, for example time constraints and reimbursement for follow-up visits. Patients did not describe this organizational structure influencing their perception or creation of respect. All clinician participants highlighted the role that continuity of care plays in relationship building. Clinicians further acknowledged that relationships are fundamental to respect in the clinical encounter, yet they realize that it is virtually impossible to have personalized relationships with the hundreds of patients in their panel. Indeed, many of the behaviors that I as the researcher assumed were respectful, and which patients also identified as respectful were also clinicians' ways of being efficient within the encounter. For example, a 'warm hand off' to the desk staff was also a way of

ending the encounter in a prompt, yet respectful manner. Letting patients set the agenda was a more effective and timely way of uncovering and understanding their concerns than clinicians setting the agenda themselves. Being flexible within the encounter and validating patient's concerns was observed by patients as highly respectful. While clinicians also identified validation as respectful, there is an underlying pragmatism that without adapting care to meet patient's needs, there is little chance that patients will be adherent. As such, both patients and clinicians describe respect in the clinical encounter in similar ways, yet there is an underlying motivation of efficiency that underscores much of what clinicians do in the encounter to be respectful of patients. Efficiency is a practical goal of clinicians and if balanced with respect leads to a win-win in clinical encounters. Efficiency becomes a negative connotation for clinicians when there is an imbalance and efficiency outweighs respect leading to unnecessary tension for the clinician in the encounter.

4.3 Question 3: How is respect related to shared decision making in the encounter?

Data from 6 clinical encounters and 11 one-hour video reflexive sessions with 6 clinicians and 5 patients was used to answer research question 3. The majority of participants were female (four of the six patients and caregiver) and (five of the six clinicians) with gender concordance among the patient/clinician dyads. Within each complex encounter there were between two and five decisions made, with an average of around three identifiable decisions being made per encounter as seen in Table 15. Decisions were identified by the researcher and shown to participants in the reflexivity sessions. Participants were asked to confirm whether these were indeed decisions that they believed were made in the encounter.

Table 15: Characteristics of the Reflexivity Sessions

Reflexivity Sessions (n=11)	Characteristics
Participants (n=12): Patient (5) Caregiver (1) Clinician (6)	 66% female 83% female
Average Length	47 minutes (sd6.8)
Average # decisions made per encounter (n=6 encounters)	3
Total decisions	18

In the reflexivity sessions participants were shown an introductory slide of the study entitled 'respect, shared decision making and the clinical encounter' and prompted with questions on decision-making as shown in Figure 2.

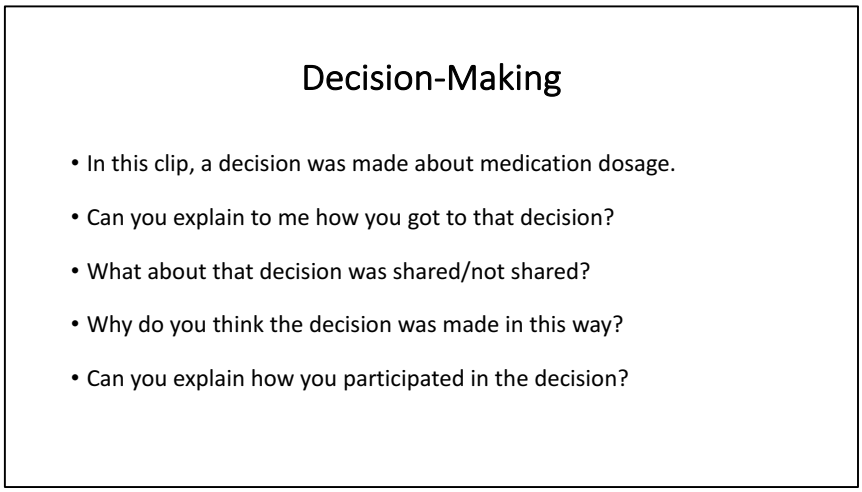

Figure 2: Slides from the power point shared with participants in the reflexivity sessions

Participants were invited to discuss their practice/appointments in the context of respect and shared decision making. After discussing what respect and shared decision making means to participants in general, video-recordings from the clinical encounters where a decision was made were reviewed. Decisions were initially identified by the researcher as moments in the encounter where a conclusion was reached after considering a topic introduced by either participant. The types of decisions that were observed in the clinical encounters and reviewed in the reflexivity sessions included medication choice and dosage adjustment decisions, consideration of alternate therapies than medications

for example exercise, switching therapy and seeking specialist consultations, ordering and timing of diagnostic testing, immunizations and continuing existing treatment. Two of the encounters involved the use of decision aids and an education tool to facilitate the decision-making process. After viewing the video-recordings, I then asked participants to reflect on the interaction and discuss how they came to the decision, who participated and whether they thought it was a shared decision, meaning that both participants made the decision together. Based on participants' responses, decisions then were categorized according to whether they were shared, led by the patient or led by the clinician as seen in Table 16. In approximately 83% of the decisions, both patients and clinicians agreed with each other on how the decision was made. In less than half of the decisions reviewed (44%) participants agreed that the decision was shared, in around a quarter (22%) of the decisions, there was consensus that the decision was clinician led and in almost 17% of decisions that participants agreed upon, it was concluded that the decision was made by patients. For the remaining decisions (16%) in which there were no consensus on who made the decision, one participant felt that it was shared while the other believed that either the patient or clinician had made the decision.

Table 16: Ways in which participants categorized decision making

		Patient			
		Shared	Clinician led	Patient led	Concordant
Clinician	Shared	44%	5.5%	5.5%	
	Clinician led	0%	22%	0%	
	Patient led	5.5%	0%	16.6%	
	Concordant				82.6%

As shown in the initial codes in Table 17, participants provided various reasons for why decisions were taken and how they participated. Initial codes were then categorized as focused codes including seeing the patient in a broader context, patients being engaged, creating a comfortable environment, the doctor as a medical expert, partnership and the patient as an expert which resulted in the three analytical themes of valuing agency, valuing feeling comfortable and valuing medical expertise. Many of these codes are similar to participants' descriptions of the characteristics of respect. A new code, trust, emerged from the analysis of the transcripts of participant reflections on decision making and informed the analytical code of valuing medical expertise.

Table 17: Coding schema for decision making

Initial code	Focused code	Analytical codes
Shared Decisions		
Addressing patient's concerns	Seeing patient as a person in a broader context	Valuing Agency
Seeking patient's input		

Table 17: Coding schema for decision making

Initial code	Focused code	Analytical codes
Knowing patient's context, preferences		
Being in control	Patients being engaged	
Empowering		
Patient's explicitly stating preferences		
Working together	Partnership, Creating a comfortable environment	Valuing Feeling Comfortable
Listening		
Making patient comfortable		
Seeking medical advice	Trust and Doctor as medical expert	Valuing medical expertise
Medically justifying		
Deferring to clinician's knowledge		
Seeing doctor as expert		
Trusting the clinician		
Clinician led decisions		
Validating patients	Seeing patient in a broader context	Valuing agency
Seeing patient in broader context		
Working together	Collaborating/ Partnership	Valuing feeling comfortable
Being comfortable with clinician		
Seeing clinician as the expert	Accepting clinician as the medical expert	Valuing medical expertise
Trusting the clinician		
Medically justifying decisions		
Patient led decisions		
Incorporating patient context	Seeing patient in a broader context	Valuing agency
Seeking patient's input		
Deferring to the patient		
Validating patient's concerns		
Expressing opinion	Patient as expert	
Clearly stating preferences		
Working together	Partnership	Valuing feeling comfortable
Trusting the clinician		
Feeling comfortable		

4.3.1 Shared decisions

As seen in Table 16, 11 decisions were considered shared (N=8 by both patient and clinician and N=3 by one of the participants). For ease of reference, Table 17 has

been divided according to those decisions that were perceived as shared, clinician and patient led. The shared decisions are included here as Table 18.

Table 18: Coding schema for decisions that were perceived as shared

Initial code	Focused code	Analytical codes
Shared Decisions		
Addressing patient's concerns	Seeing patient as a person in a broader context	Valuing Agency
Seeking patient's input		
Knowing patient's context, preferences		
Being in control	Patients being engaged	
Empowering		
Patient's explicitly stating preferences		
Working together	Partnership, Creating a comfortable environment	Valuing Feeling Comfortable
Listening		
Making patient comfortable		
Seeking medical advice	Trust and Doctor as medical expert	Valuing medical expertise
Medically justifying		
Deferring to clinician's knowledge		
Seeing doctor as expert		
Trusting the clinician		

Of the decisions that were perceived to be shared, more than half were described as shared because of patients participating in the encounter, seen through patients themselves feeling empowered and engaged when clinicians deliberately sought and incorporated patients' concerns and their broader social context into the decision making process which I saw as 'valuing agency'. The reasons associated with around 45% of the decisions being described as shared, were participants feeling comfortable in the encounter to work together in partnership to reach decisions that they could both agree to,

and this has consequences for adherence. Similarly, more than half of the decisions were also described as shared by both patients and clinicians because of a deference to clinician's authority, knowledge and experience, which contributed to patients trusting the clinician and accepting the decision based on medical justifications, what I themed as 'valuing medical expertise'.

During the shared decision making process, both patients and clinicians acknowledged the value in seeing patients in a broader context. Understanding her patient's concerns and her patient feeling sufficiently empowered to share her concerns resulted in Valerie and her clinician Sue reaching a decision together on the dosage of statin medications that Valerie would be taking. Valerie, the patient reflected, "*She's very sensitive to the fact that I am sensitive to the meds and that's respectful, she wants to make sure that I am okay if she's going to suggest a change.*" Sue her clinician agreed, "*my thought was I need to address her issues*". Even though both participants agreed the decision was shared, Sue was not sure that Valerie would be adherent because she is aware that some patients agree in the encounter but might not follow through because, "*some patients say I didn't want to make you mad or they don't want to tell you, I don't want to do that*." In another encounter, the clinician Teresa tried to incorporate her patient, Julie's concerns into the decision making process, primarily to ensure her adherence to the treatment decision. Teresa was acutely aware of her patient's body

language and could tell that she was "*hesitant, she wasn't as on board*" so she entered a negotiation with her patient Julie on the amount of a dosage increase Julie would try for her blood pressure medications, "*we negotiated what would be the target for which she would make the increase, so it was shared*". Teresa did this explicitly for Julie's buy-in and future adherence,

> "*it's a lot faster for me to tell people what to do and my day is easier but I think that for chronic disease management, if you don't have their input and buy-in, the likelihood that the plan will transpire as recommended is exceedingly low*."

While Teresa's motivation for reaching a shared decision was her patient's adherence, Julie was grateful that Teresa had understood her dislike of taking pills and had been willing to work with her and her personal preferences to reach a compromise.

Another example that participants gave of a decision being shared was when patients were able to participate sufficiently to influence the decision. Both Oliver and his clinician Adam thought the decision to change the acid reflux medications that Oliver was taking was due to Oliver's clear statement that he preferred the medication that his wife was taking. Adam shared, "*well he had already stated his preference because he didn't want the omeprazole so that part was shared and I was willing to go with that*", and Oliver expressed a similar sentiment on how they got to that decision, "*just by letting him know that I wasn't taking the omeprazole and that I was taking this other medication, and he took it from there*". Like Oliver, Valerie observed that being able to share her

personal preferences enabled her to demonstrate some control over the decision making in the encounter, and Valerie felt that she had 'the final call' in deciding the dose of the statin that she was taking. Sue, Valerie's clinician had used the statin choice decision aid in the encounter and Valerie found it helpful in discussing the risks and benefits of taking a statin, but she felt that her active participation in the decision making process "*makes me feel valid, like this is my body. I do have some control, and I can always say no, and I have said no in the past*".

In order to be able to share their personal context and raise concerns or preferences openly, some patients believed that 'feeling comfortable' contributed to their decision being shared. Lynne, an elderly patient who had suffered recently from a series of falls, identified characteristics described by other participants as respectful such as listening when she said, "*she had already established herself as a person who listens and I think that's important. I felt comfortable answering her questions*." Lynne also introduced the concept of respecting the clinician in their role as a doctor with feeling comfortable. When reflecting on her shared decision making around whether she should continue using Ambien at night for her insomnia, despite her recent falls, Lynne said, "*If you didn't have respect for the doctor you were dealing with, I think that you might feel uncomfortable following their directions.*" Another patient Ayana was going to seek a specialist consult with a cardiologist before she changed the medication that she was

currently taking, in another decision that both participants described as shared. Similarly, Ayana described having a comfortable relationship so that she could be open and work together with her clinician as respectful, "*to have that kind of relationship, you have that respect with them, they have that with you, so that you can both talk clearly and open-minded with each other*" and this led to her concluding that she would be adherent to the decision because, "*if she has enough respect for me to do that, I have enough respect to try whatever she needs to or any other doctor that she suggests*".

Finally, participants described how they shared decisions by respecting their clinician's medical expertise, knowledge and experience in a way that generated a level of trust and respect in the encounter. Indeed, the patient Julie acknowledged that while she ultimately agreed to what blood pressure medication dose she would take, she did this because "*I really trust that she [her clinician Teresa] knows what she's doing*". In another example of a shared decision attributed to respecting medical expertise, the patient Lynne also noted that when her clinician discussed with her why she should not take Ambien until they had resolved why she was falling and suffering memory loss, the decision was based on respect for her clinician's knowledge and expertise:

> "*I respected the fact that she knew that that's what we could do without any harm to me. There are times that you went to that person because they have more knowledge and experience. I just think that basic trust and respect is important for her with me.*"

Lynne's clinician Beth agreed that they had shared the decision based on medical reasons; principally that Lynne might increase her chances of falling again if she increased the dose of Ambien that she was taking. In another reflexivity session, one clinician Andrea, whose patient was unable to participate in one of the reflexivity sessions, described a shared decision for her patient to consider an alternative treatment plan because exercise and medication were not working. Andrea believed that they shared the decision because her patient respects her medical expertise, "*I do think it's a deference to an earned title or a position, I think that she is respecting my medical opinion and respecting my direction that I am going to take her care*." Moreover, Andrea suggested that "*she's a very respectful patient*", who rarely says no in deference to Andrea's authority and "*position that I am in as her doctor*."

Summary

In analyzing decisions that participants felt were shared, I developed themes of valuing agency, valuing feeling comfortable and valuing medical expertise from participants' perceptions of why decisions were shared. Valuing agency is recognizing the patient as a person in a broader context who can influence decision making by sharing their personal stories, preferences and concerns. Patients believed that they shared decisions with their clinicians when they stated their preferences clearly or when they felt

comfortable enough to raise concerns or disagree with their clinicians' treatment recommendations. One new theme of respect in the encounter emerged from participants' descriptions of sharing decisions because they trust their clinician's recommendations based on the respect that they have for their medical expertise.

4.3.2 Clinician led decisions

Table 19: Coding schema for decisions that were clinician led

Initial code	Focused code	Analytical codes
Clinician led decisions		
Validating patients	Seeing patient in a broader context	Valuing agency
Seeing patient in broader context		
Working together	Partnership and Collaborating	Valuing feeling comfortable
Being comfortable with clinician		
Seeing clinician as the expert	Trust and Accepting clinician as the medical expert	Valuing medical expertise
Trusting the clinician		
Medically justifying decisions		

The second way in which participants described making decisions was when the clinician made the decision (27% of decisions), as seen in Table 16, N=4 of 18 decisions were perceived as clinician led by both patient and clinicians and N=1 of 18 decisions the patient thought that the clinician had made the decision, when the clinician felt that the decision was shared. As seen in Table 19, participants described decisions made by the clinician when patients were seen in a broader context, where their concerns were validated and when both patients and clinicians worked together, in some cases factoring adherence into the decision making process. Being comfortable with their clinician was

another reason given for clinician led decision making. In cases where the decision was perceived by clinicians as being made by the clinician, medical indications were commonly cited as the reason.

Patients' descriptions of feeling comfortable in the encounter and clinicians seeing patients as persons and factoring their concerns into the decision making process could perhaps be a way of justifying why patients were accepting of the clinician making decisions on their behalf, and the clinician justifying why they made the decision even if it was medically justified. An example was given by Ayana, the patient and Claire, the clinician who experienced a clinician led decision to reduce the dosage of opiates that Ayana is taking. Ayana reflected that her clinician made the decision but only after validating her concerns and treating her as an expert in her own care which was respectful, "*that's very respectful because at least she understands, she's willing to think about it and say it could be but it could be this too. She understands that I understand about my body and bones*." Likewise, Claire acknowledged that in making the decision to stop the medication she was respectful, "*So I think to show respect, taking that patient's reality into account when making a decision, like how much pain are you having?"*

Clinician made decisions were often described when patients and clinicians took the patient's personal context into account and when patients believed that they were working alongside their clinicians, even if the clinician ultimately made the treatment

decision. One such case was seen in another decision that was reviewed in the reflexivity sessions of Ayana the patient and Claire, her clinician. The patient, Ayana, raised the issue of discontinuing one of her medications that she believed was no longer useful. Her clinician, Claire, felt that she should make a decision for Ayana because she knew her history,

> *"I was probably more maternalistic about that decision. She wanted to potentially come off one of her supplements but knowing that she can't absorb that from her diet and that she needs some additional supplementation, she was probably less involved with that decision. I feel like I was 90%."*

Claire explained her rationale to her patient Ayana, something that Ayana greatly appreciated because she felt her clinician understands her, "*See there she was nice enough to tell me. Any other one would say no you have to be on it. She understands me and at least she's willing to hear me out."* Ayana described her clinician making the decision as them working together because Ayana accepted that,

> "*you can get their opinion and your opinion and weave them together, you've got a solution, a happy medium because she might see something that I don't and I might see something she don't because I live with it every day*".

Ayana concluded, "*I find that respectful because I would like somebody to treat me like that too*."

A further example of taking the patient's broader context into account was seen during the reflexivity session where Adam, Oliver's clinician, reviewed an edited video-recording of decision making around medication dosage. Adam felt that he had made the

decision to increase the dosage but only after accommodating his patient's preference for one medication over another, an aspect of the decision making that Adam felt was shared,

"*It was apparent to me that the dose he was taking was insufficient. I saw that he was under-dosed and that he was putting himself at risk because he had a lot of continued symptoms, so I wanted to stay with his preferred medication but adjust the dose to an adequate level. To me, it was what I told him to do, I didn't ask him, I told him to take it twice a day."*

Even as clinicians felt that sometimes they made the decision based on medical indications, they still felt that they did so 'respectfully.' For Adam, the large amount of talking he did during the decision making process was because he wanted his patient, Oliver, to understand his motivation and Adam believed that this "*was a sign of respect as well*".

Examples of clinician led decisions made because of medical expertise were given by Andrea (the clinician) who reflected on the part of the encounter where she discussed medication treatment for osteoporosis with her patient and felt that she had made the decision. When Andrea decided that her patient should start the medication Fosamax Andrea justified her lead in the decision based on medical reasons,

"When I called her about the test results I laid the groundwork that her score of the DEXA scan was such that we should start a medication. This was an example of me taking the kind of an authoritarian 'you are going to do this', I didn't really give her options, mainly because it was such a clear indication."

Similarly, in another encounter while discussing an acid reflux concern, the patient Oliver and his clinician Adam discussed the possibility of changing medications and increasing the dosage. The patient Oliver had stated clearly that he preferred to take the medication that had been prescribed for his wife. Oliver believed that his clinician Adam made the decision to change the dosage being taken as it would be more medically appropriate. Oliver was comfortable with his clinician Adam making the decision because of his clinical expertise, "*it was his decision"* because of *"his experience. He's the doctor."*

Summary

In sum, there are decisions that both clinicians and patients feel the doctor should make because they are medically indicated. Even though these decisions are clinician led, patients felt comfortable with the clinician making the decision because they also believed that their concerns were factored into the decision, and that they understood medically why the decision was being made. Patients also respected clinicians' medical knowledge and experience. Even though clinicians led the decisions they argued that they did so by demonstrating respect in the following ways, by listening, explaining, and validating patient's concerns.

4.3.3 Patient led decisions

Patients and clinicians agreed that 22% (N=4 of 18) decisions were patient led, and another two decisions (11%) were viewed as patient led by either the patient or the clinician as shown in table 16.

Table 20: Coding schema for decisions that were viewed as patient led

Initial code	Focused code	Analytical codes
Patient led decisions		
Incorporating patient context	Seeing patient in a broader context	Valuing agency
Seeking patient's input		
Deferring to the patient		
Validating patient's concerns		
Expressing opinion	Patient as expert	
Clearly stating preferences		
Working together	Partnership	Valuing feeling comfortable
Trusting the clinician		
Feeling comfortable		

The third way that participants described decisions as being made was patient led. As seen in Table 20, when patients led the decision they cited many of the characteristics of respect that I highlighted earlier such as seeing the patient in a broader context, as an expert in their care, who is engaged and shares their values and preferences as well as working together in a trusting relationship where they feel comfortable with their clinicians.

Knowing a patient's values and concerns and the patient stating their concerns explicitly was attributed to a patient led decision in the encounter between the clinician Adam and Oliver his patient. During their encounter Adam and Oliver had a discussion

about the treatment management for Oliver's shoulder pain. The options discussed included therapy, exercise, massage, acupuncture or a referral to a specialist in complementary and alternative medicine. Both Oliver and Adam felt that the final decision to see a consultant was made entirely by the patient Oliver. Adam reflected,

"*That was definitely more explicitly, A, B, C, you choose. It was entirely up to him. Or maybe even keep doing the same, so I guess he had a number of choices and I was willing to do whatever he asked or preferred."*

Indeed, Adam felt that it was easy for him to let Oliver make the decision, and Oliver in a separate reflexivity session agreed, "*I made the decision of which person to go to*" but only after his clinician had offered options by "*listening to what my concerns are and offering solutions.*" Incorporating patient's concerns into the decision making process by offering treatment solutions that address these concerns was previously described as validation, a characteristic of respect.

Another example of a patient led decision based on the patient explicitly stating their preferences and the clinician seeing the patient in a broader context was seen in the clinician Teresa and the patient Julie's appointment. There was one incident where, although Teresa the clinician believed that medical evidence suggested a particular decision, she allowed her patient Julie to make the decision not to be immunized. Julie felt that her clinician respected her opinion, "*She respected my opinion, I'm sure that she would rather I did get the immunizations that she recommends*". Teresa, Julie's clinician

concurred that she respected the decision based on the patient in a broader context whose definition of health may differ from her clinician's,

"*At the end of the day, I feel compelled to respect that decision because again, it is their health, not mine. What their definition of health is may be different than mine, and I think that's okay so I respect that."*

Similarly, Ayana made a decision to switch her treatment therapy because her clinician saw her as an expert in her health whose opinion mattered. Claire (clinician) reflected, "*I tried to get her input on whether it was helpful or not, so she was the decision maker on whether or not to pursue a rheumatology consult and switch therapy.*" Although Ayana was the decision maker, she believes that she makes decisions within the context of a partnership with her clinician, "*I try to work with her. She's learning just as I am learning. Whatever helps, we won't know unless we try it. We're working together."* This is an example of a patient led decision that involved a degree of sharing and is associated with themes of respect such as recognizing the patient as a person and an expert in their own care as well mutual partnership and collaboration.

When Oliver made a decision to seek specialty consultation for his shoulder pain, he cited 'feeling comfortable' as one of the reasons he was able to make the decision. The patient Oliver cited many of the behaviors that emerged as defining respect in my analysis for the previous two research questions as helping him be the decision maker. He talked about the "doctor "*hearing me*" and explained that "*the comfort level that I feel*

with Dr. X allowed me to say that." At the end of the reflexivity session, Oliver offered that "*in a comfortable setting, I feel respect on both sides, I feel respected*".

Similarly, Julie also felt that she had made a decision to increase the dose of statin medication that she was already taking after working with her clinician Teresa, "*she seems to be able to work with me*." Julie felt comfortable enough to make the decision and was confident that had she disagreed entirely, "*I'm sure that she would have accepted that*." Julie described making the decision using the themes of respect addressed earlier such as patient as the expert in their care and their personal context, as well as partnership and feeling comfortable.

Summary

Patient made decisions were most closely related to the theme of respect as valuing agency. In numerous examples, patients' clear preference for a treatment modality or adjustment of their medication resulted in them making the decision. Yet, some patients needed to feel comfortable with their clinicians such that they justified making the decisions themselves in conjunction with working together in a partnership with their clinician.

Conclusion

Within clinical encounters more than one decision is often being made and the mode of decision making varies depending on medical expediency, patient preferences and working together. In describing how decisions were made, participants often included characteristics of respect described previously such as listening, understanding, seeing patients as persons in a broader context, working together in a partnership and feeling comfortable. Respect was related to decision making whether it was shared or not. In decisions that were perceived as shared, participants especially highlighted such reasons for making the decisions as incorporating patient's preferences, and patients being engaged and in control of the decision making process, which suggests to me that one aspect of respect, 'valuing agency' is fundamental for shared decision making as is 'valuing feeling comfortable'. In approximately 83% of the decisions made (N=15 of 18) participants agreed on who made the decision. In the other three decisions, at least one participant felt that the decision was shared. This difference in perception may account for why patient and clinician led decisions were also described in respectful terms. Participants can identify who ultimately made the decision, but in reflecting on the video-recordings, they may also be able to see a broader process where their expertise and engagement in the process contributed in respectful ways to the final decision being made. The appearance of respect may also mean that participants do not need to share

decisions, regardless of who makes the decision, it is accepted because of the perception of respect.

From these results, we can conclude therefore, that there is an element of respect in most decisions being made in the encounter. The ways in which participants described sharing included patients explicitly stating their preferences and clinicians taking these values and concerns into account, understanding the patient as a person in a broader context and working together within the encounter to manage the patient's health. These descriptions of sharing in the encounter are related to respect in ways that value agency, feeling comfortable and the medical expertise of clinicians.

Valuing agency as a characteristic of respect facilitates sharing when patients are empowered and engaged such that they can share their concerns and personal context in ways that affect the management of their health. Patients can work alongside clinicians in a comfortable environment that reflects respect as 'feeling comfortable'. Both patients and clinicians must work to create this feeling of comfort that engenders trust and openness in the encounter.

Valuing medical expertise is related to respect in the traditional sense of the clinician-patient relationship outlined by Parsons. Both patients and clinicians saw value in respecting the clinician for their medical expertise and knowledge. Participants were

comfortable with decisions that were medically justifiable and went further to describe sharing decision making when medical expertise was coupled with personal context.

Chapter Five
Discussion

This research describes respect from the patient and clinician's perspective. It also examines whether respect is related to shared decision making. Using video reflexivity, I uncovered how patients and clinicians, as experts in their health and health care, perceive and create respect in primary care decision making.

5.1 Respect

In answering the first two research questions, I described how patients and clinicians perceive respect in the clinical encounter. Most participants were familiar with the concept of respect. Patients, caregivers and clinicians identified respect as an important part of the clinical experience. I found that respect has moral and ethical underpinnings and is instrumental in fostering relationships in the primary care context. The link between respect and relationship centered care is not new, it has previously been described as an important factor in relationships (Beach & Inui, 2006; Hendrick, 2006; Schwalb & Schwalb, 2006). By listing attitudes and behaviors underlying relationship centered care, Beach and Inui include showing patients respect as one of the factors contributing to patients feeling respected in their healthcare relationships (Beach and Inui, 2006). While the authors discuss relationships as having a moral foundation, they do not extend this moral underpinning to respect.

Valuing individuality

I initially framed respect within Rawls' social justice theory (Rawls, 1971). Throughout the reflexive sessions both patients and clinicians spoke to the moral and spiritual characteristics of respect. For example, one clinician felt that they should see each patient 'as the face of god', while another felt that their spirituality was the frame which allowed them to treat patients equally and fairly. Other clinicians noted that respect added value to the relationship when they saw each patient as an individual within their broader social context. Accordingly, this study contributes to the literature by detailing a characteristic of respect, valuing individuality, that adds a moral component to the clinical encounter. Patients particularly described telling their stories in the encounter as respectful. Clinicians listening to patient's narratives helped them to see patients as unique individuals with lives outside of the clinical encounter. Again, I found this description of respect in keeping with Rawls' social justice theory of equally and fairly showing each individual 'proper respect' (Rawls, 1971).

Another characteristic of respect as valuing individuality is recognizing each participant as an individual with a broader personal and social context outside of the clinical encounter. Clinicians described respect when their patients showed an interest in them as persons outside of the encounter. Frequently, clinicians described their

relationships with patients as respectful when the patient was seen asking about the clinician's recent holiday or about the well-being of the clinician's family. One way that I observed for clinicians to share their stories and been seen as a person was by sharing aspects of their lives as persons outside of the encounter. This could be achieved by storytelling as well as by displaying family pictures, hobbies or plants in their offices. While the main proponents of respect in the literature have described respect as a "recognition of the unconditional value of patients as persons" (Beach et al., 2007), and impose a moral duty on clinicians to respect patients (Beach et al., 2007; Dickert & Kass, 2009; Morris, 1997; Spagnoletti & Arnold, 2007), this study concludes that respect is important for both participants. A new contribution to the literature is to describe respect as 'recognizing people as people' or 'recognizing the inherent value of the patient and the clinician as persons within their own personal and social contexts'. This broader description applies to the dyad inside and outside the confines of the clinical encounter.

Patient Agency

Here, I contribute to the literature by identifying another characteristic of respect, valuing agency as important to the relationship and the encounter. Both patients and clinicians described respectful characteristics of the encounter that helped patients exercise their agency. These included factoring how patients manage their care outside of

the encounter into the treatment discussions. For example, patients' capacity to manage their care affected when they would take their medications (in the morning with all their other pills, instead of in the evening as recommended by the clinician). Another example given was agenda setting. By setting the agenda in the encounter, patients were also able to influence what was addressed and could prioritize their concerns over the clinician's list. Patients felt respected when they perceived themselves to be empowered and active participants in the encounter. Patients as active partners has been advocated for widely in the literature (Elwyn et al., 2014; Gulland, 2011; Lau, 2002; Pulvirenti, 2011; Richards, Montori, Godlee, Lapsley, & Paul, 2013). Indeed, mutual respect is described as key to empowered patients being active partners in the encounter with clinicians (Lau, 2002). A different view is also seen in the literature. Salmon and Hall argue that empowering patients could lead to less clinical responsibility for clinicians (Salmon & Hall, 2004). Similar to Salmon and Hall's conclusion, I understood from clinicians that it would be easier to let their patients decide what's best for themselves. Yet, clinicians in this study believed that relinquishing responsibility would not be respectful. Instead, respect was described as work, as extra effort invested to empower patients to be active participants. For example, clinicians described their medical training as structured and quite prescriptive. To be respectful and co-create the agenda with patients, they had to go against the certainty offered by the clinical reasoning and ordering of the diagnostic

process obtained from idealized clinical encounters in their medical training. This was particularly difficult for younger, less confident clinicians. However, more experienced clinicians recommended being respectful by co-creating agendas and adapting care to meet patients' concerns. They found that by adopting respectful strategies they were also efficient. By relinquishing some control to patients, clinicians understood that they might save time and increase satisfaction by tailoring care to what patients want. They believed that patient ownership of their care also contributes to future adherence. In this way, clinicians' descriptions of the characteristics of respect that I call 'valuing agency' differed from patients' descriptions. Clinicians' efforts to empower patients were seen as both respectful and efficient.

Feeling comfortable

Throughout the reflexive sessions, participants described an affective element of respect which has not been sufficiently studied in prior literature. I have called this affective dimension 'valuing feeling comfortable'. Feeling comfortable is described as a co-constructed space in the encounter where participants interact with each other. The extent to which participants relate to each other in this sphere determines the extent to which respect is evident. The ways in which participants relate and affect each other may change during a clinical visit and over the course of the relationship. Participants relate to

each other in this respectful sphere, previously described by Iedema and Carroll as an 'affect-sphere' (Iedema & Carroll, 2015; Lawler, 2001). By describing respect as a co-constructed 'affect-sphere' within the broader 'spherogenics' literature (Iedema & Carroll, 2015) I aim to highlight the intangible aspects of respect that patients felt and were aware of after watching the edited video-clips. Participants' reflections of respect post video-reflexivity centered on emotions and described how they felt as well as how their actions were influenced by the other participant in the encounter. These descriptions were distinct from descriptions of respect discussed prior to the video review that focused on communications such as listening and understanding. The VRE methodology is grounded in making explicit what is previously implicit. This notion of magnifying previously hidden notions of oneself and one's clinical practices was also described as 'transforming vague cognizance into definite knowledge' (Sloterdijk, 2009). Participants' ability to see previously intangible elements of their encounter through video images has also been described previously as an affective effect of using digital media (Clough, 2008).

Initially, I thought that 'feeling comfortable' was something done for and by patients to facilitate their participation in the encounter. According to patients, clinicians contribute to the patient's comfort level by listening, understanding and reacting to the patient's non-verbal cues. Patients felt a lack of respect if they were judged or

misunderstood. Clinicians can also create a sense of comfort by encouraging patients to take the lead and introduce aspects of their personal lives into the encounter. Indeed, patients felt that they would not be able to 'open-up' to clinicians if they did not feel comfortable.

Throughout the study, it became clear that 'feeling comfortable' was also important for clinicians. Clinicians' descriptions of respect as 'feeling comfortable' differ from patients in one key regard. Clinicians are aware of the *efficiency* benefits for the encounter of their patients feeling comfortable. In this regard, efficiency is understood as performing tasks in such a way that there is minimal waste of resources, for the clinic, the clinician and the patient. Being efficient is practical and can be beneficial when it is balanced with being respectful. Clinicians know that by listening, validating patient's concerns and building a relationship with patients, they can create a feeling of comfort in the encounter. With patients that they have a comfortable, respectful relationship, clinicians would put in extra effort and do additional work. For example, they shared their personal telephone numbers providing direct access to patients. They also made after-hours follow-up calls to check on their patients. However, clinicians acknowledged that they cannot foster these kinds of relationships with all their patients, and this is challenging. They also noted that by being respectful, they were also being efficient in the encounter. Clinicians prefer their patients to be open with them, so they can meet the

patient's expectations for help. Clinicians also discussed creating an initial feeling of comfort so that they do not waste time in the encounter trying to understand the patient's health issue and broader social context. In this way, being respectful saves time while contributing to patient satisfaction. Clinicians are keenly aware of the effect 'feeling comfortable' has on these clinical outcomes for both themselves and their patients.

Cui bono (who benefits)

This study describes respect as beneficial to both parties in the relationship. I found that respectful relationships have consequences for both patients and clinicians. Respect as beneficial to patients is in keeping with previous respect studies (Beach et al., 2007; Beach et al., 2005; Browne, 1993; Dickert & Kass, 2009) but extending our understanding of respect as beneficial to clinicians as well as patients is a contribution of this study to the literature. Initially I thought that it was irrelevant if patients' perceptions of respect were based on clinician behaviors that were not genuinely respectful. Throughout the respect literature, once patients feel respected, then they will be satisfied regardless of what motivates clinicians (Beach et al., 2005; Clucas & St Claire, 2010). However, I have come to realize that for clinicians, respect also matters. While some studies have shown that clinicians perceive respect differently from patients (Beach et al., 2006; Gudzune et al., 2012), this study shows that the difference has consequences for

clinicians. Clinicians seemed to be conflicted over whether they were being respectful to patients. The resultant danger is that clinicians may begin to use what are perceived as respectful behaviors inauthentically, to improve efficiency or please the patient. I argue that this conflict can be mitigated by promoting respectful, authentic relationships (Hochschild, 1983). Clinicians felt that caring about their patients, knowing their families and their daily lives reminded clinicians why they practice medicine. They described respect as a 'gift', without which their practicing medicine would be 'moot'. When describing situations where they are suffering from burnout, clinicians agreed that having respectful relationships with their patients allowed them to retain some of the 'sparkle' of practicing medicine. Such respectful relationships might mitigate some of the effects of clinician burnout. Indeed, Apesoa-Varano and Varano (2014) suggest that 'caring' as a way of resisting conflicted institutional tensions leads to sincere social relationships (Apesoa-Varano & Varano, 2014).

Institutional barriers

Clinician burnout was also related to institutional tensions. I found that most clinicians described conflicting emotions when they spoke of being respectful while being constrained by time, access and adopting new information technology. These dehumanizing aspects of the system contribute to clinician burnout by threatening

clinicians' abilities to care for their patients in a manner deemed respectful. Wendy Simonds has also argued that the US health system is a medicalizing institution that emphasizes technology, bureaucracy and professionalism over human experiences (Simonds, 2017).

Time constraints were frequently seen as challenging to the clinicians in this study. Patients, on the contrary, often described respect in terms of the perceived amount of time their clinicians devoted to them. Although some studies have found that the length of the physician-patient encounter may be slightly increasing (Mechanic, McAlpine, & Rosenthal, 2001), physicians often perceive that they don't have enough time with patients. Clinicians have also expressed dissatisfaction with the primary focus on biomedical communication (Roter et al., 1997). Like Mechanic et al., this study suggests that a perceived lack of time may impact the clinician-patient relationship (Mechanic et al., 2001) by prioritizing being efficient in the encounter over being respectful. However, the reverse is also true. While time constraints were a challenge, I also found that for clinicians in this study, respectful behaviors were sometimes perceived as or motivated by the need for efficiency. An example was given when a clinician got a patient's wheelchair and walked them to the appointment desk; by the patient's account, this was the clinician going the extra mile to be respectful. However, this 'warm hand-off' by the clinician also ensured that the visit ended in a timely manner.

While constraints such as time may lead physicians to be less respectful here I found that respectful behaviors were a way of managing time pressures. The resultant conflict for clinicians can be burdensome.

Other examples of institutional tensions include pursuing a clinical agenda that can be reimbursed by insurers. Patients might need a follow-up visit just to check-in on their treatment management. This is not encouraged and has resulted in clinicians needing to be creative to care for their patients. Patients see this extra care as respectful, while clinicians realize that it is both respectful and burdensome. Another example was given where clinicians felt that they need to care for their patients over the phone or through the electronic patient portal, minimizing face-to-face interactions. Again, patients describe additional efforts by clinicians as being respectful while clinicians think they are more professional than respectful. In these instances, clinicians describe the 'emotional work' of doctoring. Although clinicians described respectful relationships with patients as mitigating some aspects of burnout, I found that fostering these authentic, caring, respectful relationships with patients can also be burdensome to clinicians.

The use of new information technology, the computer and entering data into the electronic health record was especially frustrating for clinicians. They described the computer in the room in strongly worded emotional terms such as 'hate' and as a distraction. The resultant tension from mastering new information technologies was

compounded by the realization that after they began to understand one system, another new system was going to be implemented. Clinicians found it challenging to multi-task in the encounter and had to devise strategies to include their patients in the process. By turning the computer screen toward patients, by explaining what was happening and that they might need to focus on entering orders for a moment, clinicians were able to bridge the divide between themselves and their patients. In the study, these best practices were evident. All the patient participants were understanding of the role information technology plays in the encounter and none described the time the clinician spent at the computer as disrespectful. Future research could study best practices in balancing the institutional demands of mastering new information technology in the encounter with being respectful of patients.

Respect as work

Specifically, being respectful involves additional work for both patients and clinicians. Respectful behaviors such as listening, co-creating the agenda, adapting care to patient's concerns took extra time and effort. It was evident that respect was part of the work done by clinicians. In addition to the work of being respectful that patients could identify, clinicians also engage in less visible emotional work. The idea of the encounter involving 'work', is also seen in the normalization literature where deliberate work needs

to occur for practices to become routine (May et al., 2009). Healthcare as burdensome work for patients is not a new concept (Shippee, Shah, May, Mair, & Montori, 2012), but the idea of respectful encounters being additional work for both patients and clinicians is.

I argue that the clinician-patient relationship can be framed as a service relationship. Like flight attendants, waitresses and nurses, clinicians are also required to engage in emotional work with (clients) patients that may be respectful. Being emotionally detached and wearing a professional mask with patients can take its toll on clinicians. Many clinicians in the study spoke about how difficult practicing primary care is. One clinician discussed self-respect and needing boundaries with patients in response to this additional emotional work. For clinicians, the work of being respectful may be leading to clinician burnout. This is especially so if the psychological costs of subjecting your true emotions is impacting the authenticity of the clinician-patient relationship (Hochschild, 1983). The often invisible tasks of emotional labor may also go unacknowledged by key health system personnel. This is particularly true when clinicians described the importance of respect as sharing personal stories and seeing both the patient and clinician as persons in the encounter. The resultant tension for clinicians of employing an emotional professional façade and wanting to engage on a personal level with patients is challenging. Participants' descriptions of the work of being respectful is akin to emotional labor in the literature, described as additional (and often

uncompensated) work that is done to manipulate real or projected feelings to satisfy job requirements and to influence the positive experience of others (Hackman, 2015). Emotional work has been investigated in the context of service oriented relationships (Leidner, 1999) such as flight attendants (Hochschild, 1983), and waitresses (Green, 2016). Other studies have also looked at emotional labor from a gender perspective for professional women (Hackman, 2015), female home-makers (Erickson, 2005) and nursing care (James, 1992).

Emotional labor is efficient for example, when respectful strategies are employed to deliberately create a feeling of comfort in the encounter. By being open and non-judgmental, clinicians are 'doing the work' that facilitates patients sharing their concerns and prioritizing what they want addressed in the encounter. This groundwork saves time in the history taking part of the encounter and will undoubtedly lead to more satisfied patients. Like Leidner (1999) who suggests that emotional work flourishes in service areas that are routine and predictable, James (1992) sees emotional labor in the daily responses to common hospital situations. Yet, clinicians in this study sought innovative ways to see each patient as an individual person, to personalize their care and in this way to make their daily practice more interesting. Trying to deal with one's emotions and manage others' emotions might result in losing touch with one's own true emotions (Hochschild, 1983) or being creative in managing the invisible effects of emotional work.

Indeed, other researchers have also questioned the cost of emotional work on clinicians (Apesoa-Varano & Varano, 2014). This study expands the respect literature by arguing that clinicians engaging in emotional work and working to challenge a professional expectation face an unrecognized and uncompensated emotional cost, resulting in some cases in clinician burnout. I further argue that the cost of being respectful should not be this high. Emotional work might be protective because it is more satisfying, and serves a purpose as it is more efficient but on the other hand it might also contribute to burnout. The contrary possibilities of 'work' in the clinician-patient relationship are not fully resolved, and are worthy of future study.

5.2 Respect and shared decision making

My third research question studied the relationship between respect and shared decision making. The interest in the connection between respect and SDM was motivated by studies showing that although SDM has the potential to improve quality of care, it has not been implemented widely. Montori et al. found that SDM in chronic care was different from SDM in acute care principally because patients play a far more active role and the decision making happens over longer periods of time (Montori, Gafni & Charles, 2006). Moreover, partnership through the patient-clinician relationship is central (Montori et al., 2006). In addressing health care that is focused on the relationship, others

suggest that respect is an important behavioral component of relationship centered care (Beach & Inui, 2006). As such, I expected that respect was key to making SDM possible. Respect is important for relationships and for patients (Quigley et al., 2014). In one study of 28 sub-specialties, respect was the most appreciated aspect of the clinician's communication style in 23 of the 28 studies (Quigley et al., 2014). In other studies, respect was rated more highly than participating in decision making (Beach et al., 2005; Beste, 2005; Joffe et al., 2003). It seemed intuitive, therefore, that respect would be important to sharing decisions in primary care clinical encounters. However, I found that respect was important in all types of decision making, shared, clinician and patient-led.

This study showed that participants embody various roles during an encounter, depending on their preference for decision making and the decision being made. Similarly, Lupton argued that patients portray a spectrum of roles, from passive patients in a paternalistic relationship to customers exercising choice in a consumerist relationship (Lupton, 1997). While prior research focused on the different roles that *patients* embraced, this study found that respect is related to how *both patients and clinicians* perceive decision making. For example, when clinicians made the final decision, they usually justified their decision making on medical necessity. They described clinician-led decision making as respectful when patients respected their medical expertise. Clinicians also described respectful aspects of clinician-led decision making where they first saw the

patient as a person. By factoring patients' personal contexts into treatment plans, clinicians felt they were respectful. As such, clinicians described adopting a dominant decision making style that was tempered by partnership before the decision was made. Likewise, when patients made decisions, clinicians described themselves as comfortable with this decision-making style because they respected the patient's expertise in their own health. Patients also noted that it was respectful of clinicians to respect their decisions, especially when they differed from what the clinician recommended. Participants agreed that over 80% of the decisions reviewed involved SDM. When decisions were shared, both participants described respectful attributes that I later coded as seeing the patient as a person in a broader social context; validating patient's concerns; feeling comfortable in the encounter and respecting the clinician's expertise. Accordingly, respect was related to SDM through both patient and clinician attitudes, emotions and behaviors. The characteristics of respect described influenced the flexibility in the roles participants adopt when making decisions and accepting why the decision is being made. Contrary to initial assumptions that respect would only be related to shared decision making, this study found that participants described varying styles of decision making respectful, regardless of who made the decision.

An exploration of SDM frameworks may help explain some of the similarities between the descriptions of respect and varying decision making styles. SDM outlined by

Charles et al. requires (1) at least two participants, clinician and patient (2) that both participants are involved in the process of treatment decision making (3) information sharing and (4) a treatment decision is made that both parties agree to (Charles et al., 1997). Participants' descriptions of decision making as two participants, listening, explaining and validating patient's concerns with a final decision being made by the clinician/patient/shared, which both participants accept is similar to the Charles SDM model. As such, various styles of decision making can be termed SDM regardless of who makes the final decision, once both participants agree to it. Therefore, it may be an artificial construct to focus on degrees of final decision making (patient-led, clinician-led or shared) instead of the broader decision making process. Indeed, expanding on the Charles et al. model, Montori et al. suggest that a key difference between SDM in acute care and shared treatment decision making for chronic conditions is the emphasis on a partnership throughout the decision-making process (Montori et al., 2006). The authors propose a model that begins with a partnership, considers bi-directional information exchange, a process of deliberating the options and deciding on a treatment, but ends with the patients having a much greater role in 'acting on the decision' outside of the encounter in their broader social context (Montori et al., 2006). Finally, earlier SDM models have been further expanded upon to focus on the 'collaborative deliberation' model (Elwyn et al., 2014). Unlike the findings in this study, the collaborative

deliberation framework does not characterize decision making by who makes the decision but by the process that precedes decision making. Given that this model closely reflects my findings of how respect relates to decision making and the clinician-patient relationship, it may be more relevant to focus on how respect is related to the decision-making *process* rather than actual decision making. The authors argue that the lead in decision making will change depending on the type of decision being made as well as participants' preferences for decision making (Elwyn et al., 2014). **Framing the findings of this study within a broader conceptual framework of shared decision making as a process based on a partnership explains why respect is related to shared decision making regardless of who makes the final decision**.

5.3 Methodological contributions

VRE methodology has traditionally been used in team-based reflexivity sessions in specialty clinical areas such as intensive care, neo-natal intensive care, surgery, pathology and emergency departments among others (Carroll, 2009; Carroll et al., 2008; Hor, 2014; Iedema et al., 2013). More recently, VRE was used in studies with patients in palliative care and hand hygiene in intensive care units (Collier & Wyer, 2016; Wyer et al., 2015). This research expanded the method even further by using VRE to explicate clinicians, patients and caregivers' experiences in primary care clinical encounters.

The practical ways in which this study contributes to the VRE method are shared here for future researchers. Researcher choice and analysis may affect future data collection (Iedema, Long, Forsyth, & Bonsan Lee, 2006). For example, Wyer et al. highlighted the effect of replaying video-footage with and without sound (Wyer et al., 2015), while Carroll noted the impact of the 'ethnographic gaze' (Carroll, 2009). This study showed that the number of camera angles used to record clinical encounters influences how participants review their healthcare experiences in the reflexivity sessions. Sharing the video-recording of a clinical encounter with the camera focused on the clinician in the foreground and the patient in the background has a different visual effect from a camera angle where the patient is in the foreground and the clinician in the background. A recommendation to be respectful of the visual effect for participants is to show clips that place the participant in the reflexivity session, in the foreground of the initial recording.

This study also expands the methodological literature by being cognizant of the amount of content shared within one edited video-recording. Previous research has noted the ideal length of a video-clip to be replayed (Iedema et al., 2013). This study complements previous recommendations in the literature by noting that participants seemed to focus on and discuss one content issue, usually the last one reviewed, if there was more than one concept played back. Accordingly, I would suggest being selective

about the amount of content included in each video-clip being reviewed in the reflexivity sessions.

Finally, like the findings of previous video studies (Clough, 2008; Iedema, 2009; Lammer, 2009) I found that VRE reveals an affective element of the research that may not be present otherwise. Previously tacit understandings of respect are brought out by the VRE methodology (Carroll et al., 2008; Forsyth et al., 2009; Iedema, Jorm, & Lum, 2009; Iedema et al., 2006).

5.4 Limitations

Setting: The setting of the study may have influenced an overall perception of respect. Research for this study was conducted in an upper Midwest academic health system, whose culture is fostered around the value, 'the needs of the patient come first' (mission statement of the study clinic, accessed January 2015). Given the prevailing culture of the health system, both patient and clinician participants may be predisposed to exhibiting behavior that is mutually respectful (Berry & Seltman, 2008). During the study, there was an ongoing Department of Patient Experience exercise. The goal of the voluntary exercise was to improve clinician communication and behaviors and to promote collaborative and healing relationships. Clinicians who participated had their encounters video-recorded and feedback delivered to them. There is a likelihood that some of the

clinicians in this study may have participated in the Patient Experience exercise. As such, they may have been exposed to many of the behaviors the literature highlights as promoting communication and relationship building. This could have affected some clinicians' descriptions of respect. The VRE methodology is grounded in the work of Jessica Mesman on 'exnovation', innovating from within (Iedema, Mesman and Carroll 2013). The method highlights a positivist approach to patient safety whereby best practices are brought to the fore. In this methodological tradition, it seems appropriate that respect be studied in a context that is well-known for its respectful culture. It is these best practices that the methodology aims to highlight.

Context: The context for this study was the clinical encounter. By focusing the analysis on a single episode, the study is necessarily limited. Admittedly, this is a small slice of the overall healthcare experience and as such cannot capture all aspects of healthcare that may influence or be influenced by respect. Given the constraints of this study and the inability to study all aspects of healthcare, this was a deliberate choice to focus on an extremely meaningful part of medical care, the clinician-patient relationship, which is fostered within the clinical encounter. The VRE methodology was chosen to counter this limitation as reviewing video footage of in-situ care has a hologrammatic effect which triggers memories of other events which may have occurred prior to the clinical

encounter itself as well as future possibilities (Iedema et al., 2013). As this study is being conducted at one point in time, it should be acknowledged that patient and clinician perspectives on the characteristics of respect may evolve over time, as has the clinician-patient relationship. As such, what is valid in this study today may not be in the future.

Selection bias: The purposeful recruitment of clinicians in this study who had previously used a decision aid may introduce a selection bias. That is, physicians may favor a shared decision making model. However, other studies have shown clinicians who use decision aids in pilots do not necessarily embrace this approach in the pilots themselves or in their future clinical practice (Inselman et al., 2016; Wyatt et al., 2014). The convenience sampling of patients may also lead to selection bias of participants who are inclined to participate in research and who for practical reasons can participate in a follow-up meeting. The VRE method is time-intensive. Participants who declined to participate in the study because of the additional time commitment may have offered different perspectives on respect from the participants in the study who could return for the reflexivity session. Patients who are disenchanted, physically or mentally vulnerable (i.e. cognitive impairment, geographic location, psycho-social disorders) and unwilling to participate due to these and other unknown factors may be the participants who could benefit the most from a study on respect. It is these unknown factors that are an

interesting missing element of the research study (Kristensen & Ravn, 2015). Yet, most patients approached agreed to participate in the study.

Social desirability bias: Patients also frequently emphasized how respected they felt in their encounters. An explanation for the mostly positive descriptions of respect is participants telling the researcher what they thought I wanted to hear, a socially acceptable response to their healthcare experiences.

Hawthorne effect and use of video: The presence of the researcher and video-recording equipment in the room is often seen as a distraction and may influence how participants act in the encounter (Henry & Fetters, 2012; Parry, Pino, Faull, & Feathers, 2016). Compared to video-elicitation studies where the video-graphic data is shown to participants without any researcher analysis, Henry also argues that relying on the researcher to edit the videos may miss 'important contextual information' (Henry & Fetters, 2012) and bias the data. The contrary is argued for VRE studies. The researcher is present as part of the ethnographic study and co-constructs the data with participants.

The potential for recall bias also exists in this study. To address this limitation, the intention was to have participants reflect on their experiences as soon after their

encounters as was convenient. Given the variability in participants' schedules, especially busy clinicians, there was a wide range in the number of days between the clinical encounter and the reflexivity sessions from 3-175 days. The average number of days for patient participants was 31 (standard deviation 34) and for clinicians was 42 (standard deviation 46). Participants may not have been able to recall their encounters three months later. However, the use of video-recordings allowed participants to distance themselves from their encounters and to observe their interactions in new ways. The method itself alleviates some of the limitations of recall bias in ways that qualitative interviews without the videographic visuals may be unable to do.

Transferability: The study was conducted at one site in a primary care setting. Given the questions to be answered, this was a high definition look at a limited number of participants in a limited study context. This choice is appropriate for answering how this select group of participants describes the characteristics of respect, what it means to them and how it is related to shared decision making in a primary care context. The intention was never to describe respect for all patients and clinicians in any setting as this would not be appropriate. Given the rich contextual descriptions of this study, if any reader believes that their setting is similar then it would be appropriate to transfer the findings. The study method could also be applied in a broader clinical context, acute settings or the

emergency department to generate a wider understanding of respect in healthcare. While the context of an academic, teaching hospital in a developed country with national policies favoring a patient-centered approach to healthcare delivery may not be transferable to other settings such as resource constrained health systems where a more paternalistic model prevails, it seems intuitive that respectful relationships may benefit participants in these settings even more so than the study context and would be worthy of future research efforts.

5.5 Implications for practice and policy

Policymakers are looking for ways to further promote patient centered care and shared decision making (Beach et al., 2007; de Haes, 2006; Fried, 2016; Legare & Witteman, 2013). Primary care has been credited with improving quality of care particularly in terms of continuity, adherence, fewer visits to the emergency department, hospitalizations and lower costs (O'Malley, Rich, Maccarone, DesRoches, & Reid, 2015). Yet, there is room for further study on how primary care teams are working to meet patients' needs (O'Malley et al., 2015). One way of improving the quality of 'good clinical practice' is through shared decision making (Elwyn, Tilburt & Montori, 2012). SDM is encouraged because of its potential to improve the quality of care delivered, by aligning care with patient's preferences and values (Oshima Lee & Emanuel, 2013) and

by reducing practice variation (Stiggelbout, 2012). SDM has the potential to improve knowledge, adherence, continuity, decisional conflict, satisfaction and in some instances, functional status and cost (Elwyn et al., 2000; Charles et al., 1997; Oshima Lee & Emanuel, 2013; Veroff et al., 2013). However, the overwhelming reason that SDM is advocated as a quality improvement tool is because it is the right way to practice medicine (Elwyn et al., 2012) for a particular patient (Kunneman & Montori, 2016). Yet, in practice SDM has not become embedded in routine care (Elwyn et al., 2014; Elwyn, Tilburt & Montori, 2012; Frosch et al., 2012; Frosch et al., 2011; Legare & Witteman, 2013). As such, further research on implementing SDM is recommended (Elwyn, Frosch & Kobrin, 2016). Previous research has relied on impractical and time-consuming reviews of encounters or survey data to measure SDM (Durand et al., 2015). The authors of this recent study questioned the efficacy of incentives for implementation based on the use of shared decision aids whose effect on SDM is difficult to measure (Durand et al., 2015). Instead, the authors suggest that further study is needed in communication and the culture surrounding the clinician-patient relationship (Durand et al., 2015). Others suggest that qualitative studies could be a complementary research methodology to ongoing big data and survey research studies (Cheshire, 2016). This qualitative study found that respect and shared decision making are related in ways that influence the culture of the clinician-patient relationship. Participants also described respectful clinical

encounters influencing their continuity of care, adherence and satisfaction with the quality of the clinical experience. Accordingly, future implementation efforts should consider respect as well as SDM, given that respectful relationships are valued throughout the decision-making process.

Respect has consequences for health outcomes (Beach et al., 2006; Beach et al., 2005; Bendapudi et al., 2006; Clucas & St Claire, 2010; Quigley et al., 2014). Here is how it matters for quality. Patients perceiving themselves to be treated with respect led to higher levels of satisfaction, adherence, preventive care (Beach et al., 2005) and familiarity with their clinician (Beach et al., 2006). In this study, clinicians were described as respectful when they exhibited certain attitudes and behaviors. Yet, respectful care was also described through less tangible and emotional aspects of the encounter. Both sets of characteristics of respect had consequences for satisfaction, continuity and adherence. As such, clinic administrators aiming to improve quality metrics should consider training clinicians in the multiple dimensions of respect described in this study. Clinicians could be trained on respectful communication styles that go beyond listening, explaining and understanding. To begin, clinicians could be reminded how important it is to 'look again, to regard' the individual in the room as more than a patient, as a person in a unique social context. This involves getting to know the patient beyond their medical diagnosis. Thereafter, to be respectful, clinicians need to

validate patient's concerns and adapt care to meet those concerns. Clinicians could also be reminded of the importance of encouraging their patient's agency in the encounter. By creating spaces for patients to set the agenda and direct their care, clinicians will be respectful. This can be achieved by ensuring that both patients and clinicians feel comfortable in the encounter. It may be more difficult to teach the affective elements of respect that participants 'saw' during video reflexivity. Especially with a concept like respect that may be difficult to grasp if it is not related to *in situ* care practices. Using VRE as quality improvement tool could be helpful for clinicians to relate their everyday practices to the conceptual descriptions of respect, particularly the intangible, affective dimensions. VRE has previously been used as a quality improvement tool by Kaiser Permanente (Neuwirth et al., 2012). Moreover, the third phase of VRE, which was not undertaken in this study, specifically aims to effect immediate practice change. The VRE methodology itself facilitates 'exnovation' or innovation from within (Iedema et al., 2013). It is the clinical teams themselves that recognize the everyday best practices via the moving images in their reflexivity sessions. By seeing and hearing how participants perceive their encounters, key stakeholders may be driven to recommend practice improvements. One can imagine that improvements may include access to scheduling that is presently outside of the control of clinicians, putting a ceiling on the number of

patients in each panel, allocating administrative time to follow-up with patients and to provide the extra care that is presently not compensated.

A further aspect to training might emphasize skills to deal with emotional work and burnout in primary care encounters. Health care within a broader institutional frame has been shown in this study to be rife with tensions leaving clinicians conflicted and on the verge of burn out. Acknowledging that clinicians who challenge this tension are putting in extra effort, which goes unrecognized and uncompensated, may be one way in which institutions can humanize care and minimize the consequences for caring clinicians.

Time constraints were shown to lead to efficient and respectful behaviors but result in additional tensions for clinicians. Addressing this tension from competing priorities for clinicians may require further research. Restructuring the scheduling of follow-up appointments so that the priority is shifted from revenue sources to relationship building might give clinicians a greater sense of control over their working environment. Fostering a partnership between patients and clinical teams has been recommended in the literature (Montori et al., 2006; Richards et al., 2013). In this study, seeing multiple members of a clinical team was not respectful to patients who favored longer-term continuous relationships with one clinician. How primary care clinics can be re-structured so that clinicians can see a smaller panel of patients is worthy of further study. Finally,

institutions that are heavily committed to evidence-based guidelines may be recommending treatments for patients that patients are resisting. When this occurs, the clinic can check the quality box that they have complied with the 'best' evidence available while the patient may be labeled non-compliant (Mulley, Trimble, & Elwyn, 2012). I believe that more respectful encounters could enable participants to feel comfortable enough to resolve these discrepancies at the time of the encounter and therefore positively affect adherence rates.

Future research should consider respect as a factor in an expanded SDM measure. The OPTION scale, described as a measure of 'the extent to which healthcare professionals involve patients in decisions within clinical consultations' (Elwyn et al., 2003) focuses on clinician behaviors, and has been used extensively to measure SDM. This measure persists even as newer conceptual models of SDM (Elwyn et al., 2016; Montori et al., 2006) highlight the collaborative and participatory nature of the deliberative process, suggesting that the role of the patient should also be considered. Other measures have emerged to address this imbalance in the OPTION scale, such as the SDM-Q-9 theoretically based measure (Kriston et al., 2010) which allows patients themselves to measure clinician behavior, and scales that acknowledge the dyad in the encounter (Kenny et al., 2010; Melbourne, Sinclair, Durand, Legare, & Elwyn, 2010). These scales have not received the uptake that the OPTION scale has. The OPTION scale

continues to be the dominant SDM measure largely because it is the most often used measure. By identifying respect as fundamental and recommending that more attention be paid to the affective sphere within which SDM manifests itself, this study can contribute to future SDM measure development.

Respect is valued by both patients and clinicians. However, it is not always easy to practice. Training and education in respect as well as re-structuring the institutional constraints that clinicians face in primary care may facilitate respectful encounters. National healthcare policies, such as the ACA, that highlight shared decision making as a means of improving healthcare, should also consider respect in the clinician-patient relationship as central to quality.

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APPENDIX I

Clinician recruitment guide

Oral consent script

You are being asked to participate in a research study about patient centered healthcare delivery. We are inviting you because you are a clinician at Mayo Clinic and you are caring for patients who present with one or more chronic health conditions and may have a discussion about treatment options using a decision aid.

Participation in this study involves video or audio-recording those clinical encounters, and subsequently, meeting again with a Mayo Clinic researcher to review the recording. If acceptable to you, the lead researcher on this study will be present during the clinical encounter for observational purposes. Notes regarding the clinical discussion may be taken but no protected health information will be recorded. At all times you will know where the recorder is and at any time you can request to stop and turn off the recording and ask that the observer leave the room. In the event of a physical exam, the video recorder will be covered and the observer will leave the room. We anticipate video-recording up to 15 clinical encounters, in this phase of our study. A member of our research team will be calling you to schedule the follow-up interview at a place and time that is convenient for you.

This authorization lasts until the end of the study. The material may be used for training or educational purposes. We will be sure to protect your confidentiality. The interviews will be de-identified and may be used for future un-identified research purposes. The study does not end until all data has been collected, checked (or audited) and analyzed. Sometimes this can be years after your study visits have ended.

The risks of this research study are minimal, which means that we do not believe that they will be any different than what you would experience at a routine clinical visit or during your daily life.

You will not receive any direct benefit from participating in this study; however, the information learned may help other patients with chronic health conditions in the future. Please understand that your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty by contacting Heidi McLeod at 507-293-0175 or Sara Dick at 507-538-3254 or dick.sara@mayo.edu. Specifically, your current or future medical care at the Mayo Clinic will not be jeopardized if you choose not to participate.

If you have any concerns, complaints, or general questions about research or your rights as a participant, please contact the Mayo Institutional Review Board (IRB) to speak to someone independent of the research team at 507-266-4000 or toll free at 866-273-4681.

APPENDIX II

Patient recruitment guide

Oral Consent Script

You are being asked to participate in a research study about patient centered healthcare delivery. We are inviting you because you have a scheduled appointment today as a patient at Mayo Clinic and you are caring for one or more chronic health conditions.

Participation in this study involves video or audio-recording your clinical encounter, and subsequently, meeting again with a Mayo Clinic researcher to review the recording. If acceptable to you, the lead researcher on this study will be present during the clinical encounter for observational purposes. Notes regarding the clinical discussion may be taken but no protected health information will be recorded. At all times you will know where the recorder is and at any time you can request to stop and turn off the recording and ask that the observer leave the room. In the event of a physical exam, the video recorder will be covered and the observer will leave the room. We anticipate video-recording up to 15 clinical encounters, in this phase of our study. A member of our research team will be calling you to schedule the follow-up interview at a place and time that is convenient for you.

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The risks of this research study are minimal, which means that we do not believe that they will be any different than what you would experience at a routine clinical visit or during your daily life.

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If you have any concerns, complaints, or general questions about research or your rights as a participant, please contact the Mayo Institutional Review Board (IRB) to speak to someone independent of the research team at 507-266-4000 or toll free at 866-273-4681.

APPENDIX III
Interview Guide

(1) Introductory question: how did you to come to be at this location for your healthcare (practice)?

(2) Thinking back to your recent appointments, can you write down three things that you liked about your experience? (If need participants to expand on what they wrote, consider asking: Can you tell me more about that?)

(3) Do you think that respect is important to you in your visits with clinicians/patients? Why?

(4) If you could describe what respect looks like to you, how would you describe it?

(5) At this time, I'd like us to watch a short video of your recent appointment at Mayo Clinic

(6) It would be really interesting to hear your thoughts on what you saw. Please take a few moments to write down on the paper provided what your initial thoughts are. (Consider prompting what the other participant thought of different parts of the video to see whether characteristics can be co-produced in this way).

(7) Did you see any of characteristics you described earlier as respectful in the video we just saw? Is there anything that you didn't see in the video, and that you would have liked to experience in your most recent visit?

(8) Here is a summary of the main aspects of respect that you mentioned. Do you think that this is an adequate summary? Have I missed anything?

(9) Of all the things about respect that we have discussed today, what do you think is the most important?

APPENDIX IV

Graphic of Shared Decision Making and Respect in Primary Care Clinical Encounters